How to Be a Resilient Caregiver

Ideas, Information and Resources for Healthy Caregiving

REVISED 2014

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Note: How to Be a Resilient Caregiver is a reference guide, and is intended for use throughout the caregiving experience. Please do not be intimidated by the scope of content provided in the manual. The information is designed to be relevant and applicable to the changing needs of the caregiver and the person receiving care over an extended period of time. Use the Table of Contents as a guide to the information that is pertinent for specific issues and situations.

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CAREGIVER CONSORTIUM

Dedication

The Caregiver Consortium, Inc. dedicates this manual to
Jessie V. Pergrin, RN, PhD
Family Caregiver, Colleague, Educator, Mentor, Community Volunteer and Friend

Acknowledgments

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Table Of Contents

Section 1. You, The Caregiver

Section 2. Caregiving and Family Relations

Section 3. LGBT Information and Resources

Section 4. In-Home Care

Section 5. Living at Home

Section 6. Understanding Alzheimer's

Section 7. Supportive Housing

Section 8. Medicare, Long-Term Care, Social Security and Veterans

Section 9. Health-Related Issues

Section 10. End of Life Issues

Section 11. Legal and Financial Issues

Section 12. Community Resources for Caregivers

Section 1

You, the Caregiver

CAREGIVER CONSORTIUM

Are You A Caregiver?

Answer the following questions to identify if you are a caregiver. Do you help someone else with:

- Maintaining normal activities?
- Housekeeping or home maintenance?
- Grocery shopping?
- Transportation?
- Bill-paying or personal finances?
- Staying in touch with friends?
- Preparing or eating meals?
- Medications?
- Dressing or bathing?
- Getting around the house?
- Remembering things?
- Hiring or supervising an in-home care worker?
- Arranging to move to a long term care residence?

If you answered "yes" to any of these questions, you are a caregiver! A caregiver is anyone who shares responsibility for another person's health, well-being and safety, no matter where they live. The individual needing help can be a relative, friend or neighbor and can be as close as your living room or as far away as a long distance phone call. Whether you help out occasionally with tasks like shopping or doctor's visits or complex situations for someone needing round the clock care, you are a caregiver.

Why Don't Caregivers Get Help?

Most caregivers identify themselves as a spouse, daughter, sibling, friend or neighbor of someone who needs help but not as a caregiver. They have a relationship with the person who needs them, so the term "caregiver" seems impersonal. There are also other common reasons why caregivers may not seek help:

- Family and Social Values - People are often taught that taking care of someone is what is expected of children, siblings, etc. and that you shouldn't get help from "outsiders".
- Guilt - The caregiver may worry that the person getting help will be upset if someone else takes his/her place so the caregiver can have a break.
- Fear - The term might frighten the caregiver because of the responsibility it implies.
- Cost - Paying for outside help might cause financial hardship.

The demands of caregiving can become difficult and stressful. It can have a negative impact when you, the caregiver, become exhausted, overwhelmed or resentful. Help is available now. Call:

Pima Council on Aging
Primary source for assisting older citizens, including caregivers.
Help Line 790-7262

Source: Caregiver Consortium

Caregiver Self-assessment Questionnaire: How are YOU?

Caregivers are often so concerned with caring for their loved one's needs that they lose sight of their own well-being. Take a moment to answer the following questions.

During the past week or so, I have…

1. Had trouble keeping my mind on what I was doing.	Yes	No
2. Felt that I couldn't leave my relative alone.	Yes	No
3. Had difficulty making decisions.	Yes	No
4. Felt completely overwhelmed.	Yes	No
5. Felt useful and needed.	Yes	No
6. Felt lonely.	Yes	No
7. Been upset that my relative has changed so much from his/her former self.	Yes	No
8. Felt a loss of privacy and/or personal time.	Yes	No
9. Been edgy or irritable.	Yes	No
10. Had sleep disturbed because of caring for my relative.	Yes	No
11. Had a crying spell(s).	Yes	No
12. Felt strained between work and family responsibilities.	Yes	No
13. Had back pain.	Yes	No
14. Felt ill (headaches, stomach problems or common cold).	Yes	No
15. Been satisfied with the support my family has given me.	Yes	No
16. Found my relative's living situation to be inconvenient or a barrier to care.	Yes	No
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.		
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.		

Caregiver Self-assessment Questionnaire: Scoring

Reverse score questions #5 and #15. (For example, a "no" response should be counted as «yes» and a «yes» response should be counted as «no».)

Total the number of «yes» responses. Chances are that you are experiencing a high degree of distress if you answered "Yes" to either or both Questions #4 and #11; **OR** if your total "Yes" score is 10 or more; **OR** if your score on Question #17 is 6 or higher; **OR** if your score on Question #18 is 6 or higher.

Next Steps

- Consider seeing a doctor for a check-up for yourself
- Consider seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving
- Consider joining a support group.

Source: American Medical Association

The Resilient Caregiver –
Challenge and Opportunity

By: Jan E. Sturges, M.Ed., LPC
Caregiver Consortium

In these historic times of social and economic unrest, most of us do our best to believe that, at the end of the day, our glass will remain half-full and not half-empty. Although we may become discouraged by the stressors of daily life, these challenges make us stronger when we take the opportunity to savor special moments with people who are important to us. We are practicing serendipity – the act of transforming adversity into inspiration.

Caregivers - individuals who have responsibility for the safety and well-being of a dependent person — understand what it's like to live with uncertainty, and to be persistent in the face of exhaustion and worry. They become attuned to the power of compassion that emanates from attending to the physical, emotional and spiritual needs of the person in their care. This is serendipity in action - the ability to "get up and dust yourself off" after the daily pitfalls of caregiving. It gives individuals the strength to move beyond surviving to thriving – for a few minutes, a few days, a few years.

Serendipity is also characteristic of resiliency - the "bounce back-ability" to achieve your personal best as a result of difficult times - and the wisdom to respond (not react) to changing circumstances. Resilient people are flexible and creative – they flow with change instead of resisting it, and focus on the value of being instead of doing.

In Ageless Body, *Timeless Mind,* Deepak Chopra, M.D. says that "the wisdom of uncertainty" is a source of growth, understanding and acceptance. We may not always enjoy the process, but the experience of caregiving can create healing and resolution. We learn to adapt when we accept the fact that our mother, wife, brother, friend may not "get better," and that both caregivers and care receivers may need to make sacrifices to accommodate one another's needs.

So, how do caregivers balance their own needs with those of the person who depends on them? How do they manage day-to-day caregiving responsibilities in addition to the pressures of family, work and other obligations? Here are a few tips from resilient caregivers:

- Give yourself unceasing credit for your efforts. Whether you are providing care for someone out of love or obligation, you are improving the person's safety and well-being.
- Set realistic expectations for yourself. Ask for assistance from family members, friends, health care professionals, and community agencies that serve dependent individuals.
- Seek support from family members, friends, counselors, spiritual advisers or other caregivers with whom you can share your woes, joys, problems and successes.
- Make a commitment to your physical, mental, emotional and spiritual well-being by replenishing your energy with relaxation, recreation and time for yourself.
- Connect with the person in your care by creating a peaceful space to reminisce, share experiences and be comforted.

Author Richard Bach refers to serendipity by saying, “There is no such thing as a problem without a gift for you in its hands.” This is the heart of resiliency for caregivers. Our goal is to rise to the challenge without denying the full spectrum of difficulties and delights, and to believe that our caregiving relationship has meaning – both for ourselves and the person receiving care. Whenever we involve ourselves in the life of someone who is vulnerable, we are on hallowed ground.

Rev. 3-14

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Advocacy, Action, Assistance

The Caregiver’s To Do List

By: Laura Michaels, MSW

When you are caring for another person, you may find yourself with a long “To Do” list on a regular basis. Lists can be very helpful in keeping you organized and reminding you of tasks to complete. However, although their lists are filled with things to do for other people, caregivers often forget to include some of the most important tasks of all—the ones that will enhance and protect their own physical and emotional well-being. Below are some “to do’s” that you may want to place on your list:

- Breathe. You may be breathing enough to keep you alive, but odds are you aren’t breathing deeply enough to keep your body energized and your mind clear. Try breathing in through your nose, inflating your belly, then exhaling slowly through your mouth as your belly deflates.
- Drink Water. Even mild dehydration can alter a person’s mood, energy level, and ability to think clearly. You have heard it before, and for good reason, drink at least eight, 8-ounce glasses of water a day.

> Keep your body energized and your mind clear.

- Nourish Your Body. We all know how we are supposed to eat but it’s hard when you are eating on the go, not eating regularly, or just looking for a quick pick me up to boost your mood. It’s very important to plan your meals and snacks ahead of time (when you aren’t tired or hungry) and keep healthy choices handy so you can keep your blood sugar – and mood – stable.
- Sleep. This one can be tough when there aren’t enough hours in the day to get everything done, or the person you care for gets up frequently at night. However, getting those 6 to 8 hours of shut eye is important because sleep deprivation can cause problems such as irritability, difficulty concentrating, poor memory, and impaired driving ability. Try to wind down at night and create a ritual that your mind and body identify with bedtime. A warm shower, writing in a journal, reading, meditating, taking deep breaths—whatever will help you shut down your over-worked mind and relax.

> It’s important to get time away from the person you are caring for.

- Move Your Body. Just about any exercise can be of benefit to your physical, emotional, and mental health if you do it on a regular basis. There are many options such as walking, dancing, stretching, lifting hand weights, swimming, taking Martial Arts classes, using exercise DVD’s, and others. Just find something that you enjoy and commit to doing it at least three times per week. It can improve your mood, cognitive abilities, energy level, and overall health.

Okay, those are all crucial and life-sustaining suggestions. One of equal importance is to take a break. It’s important to get time away from the person you are caring for. Even if you don’t live with your care recipient, you need time to spend on your own interests without worrying about getting “the call” saying your attention is needed because no one else can help. Line up a family member, neighbor, friend, paid caregiver, respite stay at a facility, adult daycare—whatever it takes to get some time off.

Additional Suggestions:

Decide what you will and will not do for your care recipient and what behavior you will and will not accept from them.

- Set Boundaries – Decide what you will and won't do for your care recipient and what behavior you will and won't accept from them. Make it as clear to them as you can and stick with what you say. When you behave in new, self-affirming ways instead of repeating old patterns, you may see a difference in the way the other person responds.
- Laugh – As often as you can. We all have "sitcom moments" in our lives when things are just so ridiculously awful they are funny. Read a book from the humor section of a bookstore, watch a funny TV show or DVD, look-up a website filled with jokes and silly pictures – just do something that will make you smile.
- Write in a Journal – Sometimes getting your thoughts down on paper can be cathartic. It can be a safe way to express the feelings churning inside of you. Writing a letter to someone that you never intend to give them can be another way to release some emotions that are troubling you.
- Meditate and/or Visualize – It doesn't have to be anything fancy to be helpful. Focus on your breath while thinking a word or phrase that makes you feel calm and relaxed. You can also picture a beautiful place and see yourself there. Create a scene so real that you feel the breeze blowing, smell the flowers, and hear the sounds of the brook – whatever works with your image.
- Give Yourself Some Credit – You are helping another person in a meaningful way – that's a truly generous gift. It's true your care recipient may not always be appreciative. They may refuse your advice or take out their frustrations on you. At those times it might help to focus on why you have chosen to be a caregiver and what about it you find rewarding or important. And be compassionate towards yourself. Some days you may be on top of things and get a lot accomplished, and other days you may feel worn out and just want to hide. What's important to remember is that none of us are perfect and that's okay. You are still performing a great service to another human being and you deserve applause, not self-recriminations.

Above and beyond all else, *take good care of yourself!*

Tips for Caregivers

Edited by: Jan E. Sturges, M.Ed., LPC
Caregiver Consortium

The caregiver tips and suggestions listed below do not come from just one source. They are pearls of wisdom and practical suggestions that have evolved from the collective experience of family and professional caregivers over time.

The Caregiver Relationship and Well-Being

- Give yourself unceasing credit for what you are contributing to the life of the individual for whom you are providing care. Whether or not you are a caregiver out of love or obligation, you are undoubtedly adding a dimension of quality and dignity to the person's existence that might not otherwise occur.
- Keep track of your own physical and medical well-being; whenever possible, get a minimum of six hours sleep a night.
- Avoid using drugs and/or alcohol as a remedy, or as a replenishment for fatigue.
- Learn one or two quick and simple relaxation and self-affirmation exercises, and practice them daily. Making this commitment to your own well needs will benefit your care recipient, too. Maybe you can practice a relaxation exercise together.
- Take some time each day, if possible, to write down your thoughts and feelings about caregiving in a journal. List problems and successes as well as short-term and long-term goals. Keep them realistic.
- Develop and maintain regular, planned events that are pleasurable and relaxing. They offer you an opportunity for self-renewal.
- Never feel guilty about taking time for yourself, and enjoy it, even if your loved one is unable to participate.
- Give up unrealistic expectations of yourself, the person for whom you are caring, and others who assist with care. Have the courage to be imperfect.
- Be prepared to reach compromises with your time and effort as well as that of the person who depends on you.
- Spend quality time with your loved one or the person receiving care.
- If your loved one is mentally and emotionally capable, take a risk by sharing some of your thoughts and feelings about what is happening in an honest, but respectful way. Come to some agreement about each other's limitations as well as strengths. Learn to share your fears, and most importantly, learn to share your hopes.

Resources for Caregivers and the Person Receiving Care

- Assess your resources: People, environmental (housing, location, safety/home modification/ assistive devices), finances, health care, time, energy, spiritual support.
- Use problem-solving techniques when you are facing a difficult circumstance: define the problem; brainstorm ideas for solving it; prioritize what activities are necessary to address the situation; implement them i.e., take action; evaluate the results.
- Plan ahead by making sure that all financial and legal documents are in place including an estate plan/will and testament or trust, advance directives (Living Will, Health Care and/or Mental Health Care Power of Attorney, Pre-Hospital Medical Directive – Do Not Resuscitate), Durable Financial Power of Attorney, investments and insurance policies.
- If you hire home care workers or respite workers, supervise them enough so that they are accountable without micro-managing them. Treat them as part of the "team" that is giving care – trust encourages people to do a better job.
- Learn to accept help and to respect the fact that others may provide assistance in ways that are different than yours. They may also demonstrate care and concern differently.
- Ask for other family members, friends and professionals to help you. Remember - you, your loved one and the people who assist with caregiving are part of the same team. Be specific and direct in explaining what you want them to do, or what you need.
- Seek out and cultivate at least one professional (mental health professional or spiritual adviser) who understands the impact of your caregiving experience. Maintain regular contact with this person, and evaluate both your challenges and your successes.
- Allow yourself to find the humor in caregiving, and seek ongoing contact with friends and others who are upbeat, and who will listen to you when you need a boost.
- Participate in a caregiver support group. You will discover that you are not alone in this experience, and you will gain invaluable suggestions and ideas from other caregivers.

AARP®
Real Possibilities

Tips for Working Caregivers

If you are a working caregiver, you know what it's like to be a nonstop juggler, trying to have a life while keeping some balance among responsibilities. Your caregiving role may be hard, even overwhelming, but there are steps you can take that may ease the burden.

Symptoms of Stress

Health: Many working caregivers report health problems, depression, lower productivity on the job, and lost time at work. If you are frequently distracted at work, emotionally drained, and physically exhausted, you are not alone. But do not ignore these symptoms. Recognizing them is the first step to finding solutions.

Relationships: You may also find that you have let your social relationships slide. Many working caregivers cut back on community involvement and spend less time with their own families. If this is happening to you, make every effort to rekindle friendships and reconnect with your community—for example, through church or another group. You will be better able to deal with stress if you have a support network.

Steps You Can Take

1. Talk to your employer. Let your manager know your needs related to caregiving. Make it clear that you are committed to your job and want to find ways to remain productive.
2. Resist isolation. Find support in and out of work. Join community caregiver groups for emotional support, and seek out local resources for help. Take advantage of resources, such as Lotsa Helping Hands, to coordinate caregiving tasks within your family and support network.
3. Take care of yourself so that you can take care of others. As often as you can, get enough sleep. Eat sensibly, use alcohol in moderation, and exercise. Take a break when the pressure gets too great, even if it's just a hot bath or a short walk. Walking with a buddy can cover two needs at once—friendship and exercise.

Know Your Rights

Consult with human resources about what you are entitled to under the law. The Family Medical Leave Act (FMLA) requires large employers to provide up to 12 weeks of unpaid time off with job protection when workers must care for a sick or injured parent. Some states have extended this coverage to include small businesses as well.

Take Advantage of Benefits

- Ask about flexible-work options. This could mean a compressed work week or a modified daily schedule based on need. Job-sharing and telecommuting are also caregiver-friendly options to explore. Many employers offer flexible work options on a case-by-case basis even if there is no formal policy.

- Contact your Employee Assistance Program (EAP) and find out what support services are available, such as counseling on reducing stress and managing your time.
- Many companies offer access to eldercare referral services through an online database or live consultants. Such services reduce the burden of having to do distracting and time-consuming research.
- Respectfully share information with your manager or HR on how employers can support working caregivers.

Build a Support System

- Connect with other caregivers at your place of work. It's likely that some of your fellow workers face the same caregiving challenges.
- Put in a request to human resources to sponsor brown bag lunches or an employee resource group to help with caregiving issues. Or you could organize your own informal group to meet during your lunch hour.
- Thank your coworkers who take on extra assignments or help you with work projects. They are part of your community, too.
- Make sure your manager knows about your accomplishments at work. This will show you are able to deal with multiple priorities.
- Join the caregiving group on the AARP Online Community to share your story, get support, and connect with other caregivers.

Plan for the Future

When it comes to caring for an aging loved one, most families don't have a plan until there is a problem. But as many working caregivers have discovered, the stress of making caregiving arrangements in "crisis mode" can be overwhelming. AARP's Prepare to Care: A Planning Guide for Families is a step-by-step guide for creating a caregiving plan in advance. Even if you have been a caregiver for years, the guide can help you get support and stay organized. Tell your employer about it!

Other articles on the AARP website: www.aarp.org

Source: AARP

alzheimer's association®

Desert Southwest Chapter

Caregiver Stress
Warning Signs & Steps to Take

"I DON'T HAVE TIME TO TAKE CARE OF MYSELF"

Sound familiar? If so, you may be putting yourself at risk. As an Alzheimer's caregiver, you devote a significant amount of time and energy to the person with Alzheimer's disease. You are likely to experience moments of stress, and anxiety that may be severe. Too often, caregivers don't recognize their own needs, fail to do anything about them, or simply don't know where to turn for help. For these reasons, the Alzheimer's caregiver is often called the hidden or second victim, of the disease.

10 SIGNS OF CAREGIVER STRESS

Too much stress can be damaging to both you and the individual that you are caring for. The following stress indicators experienced frequently or simultaneously, can lead to more serious health problems. Learn to recognize signs of stress in yourself. Taking care of yourself will help you be a better caregiver.

1. **Denial** about the disease and effect on the person who's been diagnosed.
   "I know mom is going to get better"

2. **Anger** at the person with the disease or others that no effective treatments or cures currently exists; and that people "don't understand what's going on. "
   "If he asks me that question one more time, I'll scream"

3. **Social withdrawal** from friends and activities that once brought pleasure.
   "I don't care about getting together with the neighbors anymore"

4. **Anxiety** about facing another day and what the future may hold.
   "What happens when he needs more care than I can provide?"

5. **Depression** begins to break your spirit through apathy and affects your ability to cope.
   "I don't care anymore."

6. **Exhaustion** makes it nearly impossible to complete necessary daily tasks.
   "I'm too tired to do this."

7. **Sleeplessness** caused by worry over a never-ending list of concerns and anxiety.
   "What if she wanders out of the house or falls and hurts herself?"

8. **Irritability** leads to moodiness and triggers negative responses and reactions.
   "Leave me alone!"

9. **Lack of concentration**, which makes it difficult to perform familiar tasks.
   "I was so busy; I forgot we had an appointment."

10. **Untreatable** health problems which begin to take their toll, both mentally and physically.
    "I can't remember the last time I felt good."

10 WAYS TO HELP REDUCE CAREGIVER STRESS

Unfortunately, the ultimate stress reducer- a cure for Alzheimer’s disease- has not yet been discovered. But there are programs, services and care techniques that can help. To assist you in providing the best possible care, while maintaining you own health and well being, the Alzheimer's Association suggests the following:

1. **Get a Diagnosis as Early as Possible**
   Symptoms of Alzheimer’s may appear gradually, and if a person seems physically healthy, it’s easy to ignore unusual behavior, or attribute it to something else. Seeing a physician, when warning signs are present (please see, *Is It Alzheimer’s? Ten Warning Signs*, available from the Alzheimer's Association), some dementia symptoms are treatable. Once you know what you’re dealing with, you’ll be able to better manage the present and plan for the future.

2. **Know What Resources are Available**
   For your own well-being and that of the person you are caring for, become familiar with Alzheimer’s care resources available in your community, Adult day care, in-home assistance, visiting nurses and Meals-on-Wheels are just some of the community services that can help. The Alzheimer's Association Desert Southwest Chapter is a good place to start.

3. **Become and Informed Caregiver**
   As Alzheimer’s disease progresses, different caregiving skills and capabilities are necessary. Care techniques and suggestions available from the Alzheimer's Association can help you better understand and cope with many of the challenging behaviors and personality changes that may

4. **Get Help**
   Trying to do everything by yourself will leave you exhausted. The support of family, friends, and community resources can be an enormous help. If assistance is not offered, ask for it. If you have difficulty asking for assistance, have someone close to you advocate for you. If stress becomes overwhelming, don’t be afraid to seek professional help. Alzheimer's Association support group meetings and Helpline are also good source of individualized comfort and reassurance.

5. **Take Care of Yourself**
   Family caregivers frequently devote themselves totally to those they care form and in the process, neglect their own needs. Pay attention to yourself. Watch your diet, exercise and get plenty of rest. Use respite services to take time off for shopping, a movie or an uninterrupted visit with a friend. Those close to you, including your loved one with Alzheimer’s disease want you to take care of yourself.

6. **Manage Your Level of Stress**
   Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Note your symptoms. Use relaxation techniques that work for you and consult your primary care physician.

7. **Accept Changes as They Occur**
   People with Alzheimer’s disease change and so do their needs. They often require care beyond what you can provide at home. A thorough investigation of available care options should make transitions easier. So will assistance from those who care about you and your loved one.

8. **Do Legal and Financial Planning**
   Consult an attorney and discuss issues related to durable power of attorney, living wills and trusts, future medical care, housing and other key considerations. Planning now will alleviate

stress later. If possible and appropriate, involve the person with Alzheimer's and other family members in planning

9. **Be Realistic**
   Until a cure is found, the progression of Alzheimer's disease is inevitable. The care you provide does make a difference. Neither you nor the person with Alzheimer's can control most of the circumstances and behaviors that will occur. Give yourself permission to grieve for the losses you experience, but also focus on the positive moments as they occur and enjoy your good memories.

10. **Give Yourself Credit, Not Guilt**
    You're only human. Occasionally, you may lose patience and at times, be unable to provide care the way you'd like. Remember that you're doing the best you can, so give yourself credit. Being a devoted caregiver is not something to feel guilty about. Your loved one needs you and you are there. That's something to be proud of. If your loved one could, they'd thank you.

The Alzheimer's Association® is the only national health and social service organization dedicated to research, and to providing support and assistance to people with Alzheimer's disease, their families and caregivers. Founded in 1980, the association works through a network of more than 80 chapters across the country.

The Alzheimer's Association Desert Southwest Chapter provides programs and services to tens of thousands of families including Helpline – a 24/7 assistance line, MedicAlert®+Safe Return®, Family Care Consultation, Support Groups, Education, Early Stage Programming and Legislative Advocacy. Please, contact us for any more information or assistance, 24 hours a day, seven days a week, at 800.272.3900 or online at www.alz.org/dsw.

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Taking Care of the Caregiver

Learning How to Cope with Caregiver Burnout

When someone is diagnosed with cancer, the patient is not the only one affected. The person responsible for care is also affected. Providing care for a loved one with cancer can be very stressful. When caregivers don't attend to their own needs and allow other pressures to take over, they lose the ability to continue to care for the loved one or friend. This condition may be known as burnout.

Recognize the Signs of Burnout:

- Irritability. You snap at people for small things; you lose patience easily.
- Withdrawal. You don't stay in touch with friends and activities like you used to.
- Fatigue. You are constantly tired and exhausted.
- Insomnia. You have a hard time getting to sleep, staying asleep, or sleep restlessly.
- Apathy. You feel numb and must force yourself to do routine caregiver tasks.
- Appetite Changes. You eat more than you used to, or don't feel like eating anything.
- Increased Substance Use. The only relief you can get is from alcohol, drugs, or smoking.
- Feelings of Guilt. You think you are not doing enough, or you feel resentment for the amount of work you are doing.

What to Do:

In order to care for someone else, you must take care of yourself. Your mental and physical health is just as important as the patient's, so it's important to recognize your limits. Be aware of how much you can do, as well as what you cannot do. You are not super-human. Don't feel guilty when you take time to re-energize yourself.

1. Exercise. Even if you do not have time for a formal workout, incorporate exercise into your daily routine. For example, take a walk around the doctor's office or hospital grounds during the patient's appointment.
2. Eat properly. Many times caregivers are so absorbed in preparing patient meals they neglect their own nutritional needs.
3. Read. For pleasure, or for information, reading can be a wonderful outlet for stress and anxiety.
4. Get a massage. Many people think that they need to spend all their money on medical bills and if they spend money on personal needs, they feel guilty. Getting a massage may not be that expensive. Many major cities have massage schools with low-cost student clinics.
5. Pursue hobbies. Don't lose touch with the things that gave you pleasure before your loved one became ill. Whether it is gardening, music, or art classes, continue to do what brings you joy, even if it is less frequent than before.
6. Practice relaxation techniques. Whether it's progressive muscle relation, visual image or deep breathing, anyone can incorporate these skills into their daily lives. Many stress management workshops and books are readily available.

7. Keep a journal or diary. It's helpful to use this as a way to keep track of what you are going through and how you are feeling.
8. Tap into your support network. Don't be afraid to ask for help. Many people want to help but don't know what to offer. Ask friends, relatives, neighbors, co-workers, or people in your church or synagogue to help out with some tasks.
9. Blow off steam. Go to the movies, go to dinner, have fun, play games. It's okay to escape and not focus all your energy on your loved one's illness. They want you to be able to enjoy life.
10. Join a caregiver's support group. Contact your local American Cancer Society to find the nearest group. It's important to connect with people who share similar experiences.

Adapted from the American Cancer Society website www.cancer.org
Article date: 06/11/1998

Caregivers and Exercise—Take Time for Yourself

Taking care of yourself is one of the most important things you can do as a caregiver. Finding some time for regular exercise can be very important to your overall physical and mental well-being.

Physical activity can help you:

- Increase your energy level so you can keep up with your daily caregiving activities.
- Reduce feelings of depression and stress, while improving your mood and overall well-being.
- Maintain and improve your physical strength and fitness.
- Manage and prevent chronic diseases and conditions like diabetes, heart disease, and osteoporosis.
- Improve or maintain some aspects of cognitive function, such as your ability to shift quickly between tasks and plan activities.

Some ways for caregivers to be physically active:

- Take exercise breaks throughout the day. Try three 10-minute "mini-workouts" instead of 30 minutes all at once.
- Make an appointment with yourself to exercise. Set aside specific times and days of the week for physical activity.
- Exercise with a friend and get the added benefit of emotional support.
- Ask for help at home so you can exercise.
- If possible, find ways to be active with the person you're caring for. Both of you can benefit from physical activity!

✓ *Quick Tip*

Pick an activity you really enjoy to make exercise something you *want* to do, not *have* to do.

VISIT
www.nia.nih.gov/Go4Life

- Read more tips for adding physical activity to your day.
- Print useful tools.
- Order a free exercise guide or DVD.
- Share your exercise story.

National Institute on Aging
National Institutes of Health
U.S. Department of Health & Human Services

The 'Art' in the Heart of Caregiving:

Quick and Easy Relaxation Techniques

Breathing

One of the best stress reducers and calming techniques available to each of us is something we do 24 hours a day without thinking about it – breathe! However, the key to breathing as a means of decreasing stress and improving performance is intentional breathing. Breathing with purpose allows you to become centered and focused, and allows you to experience the timelessness of the present moment. Intentional breathing improves blood flow, decreases your heart rate and blood pressure, and therefore, increases life-saving circulation of oxygen to all your cells. This, in turn, creates an environment for self-healing. Here are some techniques for proper breathing:

1. Find a relaxing environment, if possible, and sit comfortably with your eyes closed. Make sure all extremities are uncrossed. Sit up straight enough to give your diaphragm room to expand.
2. Pay attention to the rhythm of your natural breathing, and tell yourself to "let go of all thoughts and feelings for now."
3. Inhale through your nose to the count of four, hold your breath for a moment, and then exhale slowly through pursed lips to the count of four. Breathing should be slow, deep and regular.
4. Repeat this exercise several times until you begin to feel yourself "letting go." You may feel a slight tingling or warmth in your hands and feet – a sign that there is increased blood flow to your extremities. It only takes 3 or 4 deep breaths like this to return your body to a state of calm.

Body Scan (5 minute maximum)

This is a good technique to use whenever you need a quick stress-reducer.

Sit comfortably with your eyes closed. You are going to scan your body starting at your head and going down to your toes to see if there is any tension. As you do this, breathe slowly and deeply. Keep the pattern regular. Every time you exhale, become even more relaxed. As you look at each muscle group, check to see if there is any tension. If there is, just let it go. For example, check your forehead and eyes. If you feel any tension, release it. Say, "forehead let go," or "eyes let go." As you progress through the muscle groups, periodically recheck your breathing to make sure it is slow, deep and regular – relaxing even more with each exhalation. Go through the muscle groups in the sequence listed above.

When you are finished, quickly rescan your body starting at the head and working down to the feet. Wherever you spot tension, just release it.

- Resources for Body Scan from J.M. Williams, Ph.D.

Edited by: Jan Sturges, M.Ed., LPC

The Holiday Spirit – From Harried to Heartfelt

By: Jan Sturges, M.Ed., LPC
Caregiver Consortium

Holidays at any time of year are about staying connected to the values, people and experiences that enrich us; they acknowledge the importance of our relationships by highlighting the joys of the past and by giving us the opportunity to create memorable moments that will nourish us in the future, when we need to be uplifted.

For caregivers, the holidays can be particularly challenging when they are caring for a loved one in declining health. They may have conflicting emotions about how they 'should' feel ('happy' and 'merry'… isn't that what holiday songs suggest?) vs. how they really feel (sadness or sorrow) because it is no longer possible for family and friends to enjoy past traditions and celebrations due to illness or dementia. And, how can caregivers add holiday-related tasks and activities to the long list of caregiving responsibilities they already have, in addition to work and family obligations?

Below are a few caregiver 'Tips and Treasures' for coping with holiday stress that have been assembled from many different sources. You can also go to the following websites for additional online information:

www.caregiver.org/caregiver/jsp/home.jsp
www.caregiver.com/articles/holiday/holiday_stress_caregiving.htm
www.alz.org/living_with_alzheimers_holidays.asp

Tips and Treasures for Caregivers

- Mindfulness – Focus on the intrinsic values of the holidays – stay connected to people and relationships – and participate in one or two meaningful events (not ten or fifteen!) that will nourish you, your family and friends. Instead of cooking a large meal, host a pot-luck party, attend a holiday concert or participate in a faith celebration.
- Compassionate presence - Set aside time to include the elder or dependent person in practical, but meaningful, non stress-producing activities. Even if they are not able to participate or converse at length, your compassionate presence and 'being' vs. 'doing' will create a caring bond.
- Priorities - Set realistic expectations for activities and gift-giving based on your resources – people (family, friends, community resources, and professional health care providers), time, finances and energy.
- Traditions – Decide what past traditions are no longer appropriate, and develop a few new ones. Combine some of the 'old' with the 'new' and create a different set of holiday traditions without comparing them to 'the way it used to be.'
- Affirmations – Be kind, and acknowledge disappointment without judging yourself or others when life gets messy during the holiday rush.

- Self–care:
    - ➢ Eat, drink and be merry, but not too much! Balance sugar and alcohol intake with healthier foods.
    - ➢ Allow yourself a 'time out' every day. Take four deep breaths, walk around the yard, read a few pages of a book or listen to music. (Really, you can do this!!)
    - ➢ Arrange for someone to stay with the person in your care while you attend a social event, or complete some of the tasks on your simplified To Do list.
    - ➢ Find a supportive person who can help you solve problems that arise, or listen to your concerns about caregiving during the holidays.
- Humor – Give the gift of laughter to yourself and others, and relax!

References:
Family Caregiver Alliance, 'Managing Caregiver Stress'
Hope Publications, 'How to De-Stress the Holidays'

Caregiver Depression: Prevention Counts

Caregiver depression can take a toll on you and your ability to care for your loved one. Understand the signs of caregiver depression - and know how to prevent it.

Caregiving is often physically and emotionally stressful. In an effort to provide the best care possible, you might put your loved one's needs before your own. In turn, you could develop feelings of sadness, anger and loneliness. Sometimes, these emotions can trigger caregiver depression.

What are the symptoms of caregiver depression?

Everyone has a bad day sometimes. However, to be diagnosed with depression - also called major depression - you must have five or more of the following symptoms over a two-week period. At least one of the symptoms must be either a depressed mood or a loss of interest or pleasure. Symptoms include:

- Depressed mood most of the day, nearly every day, such as feeling sad, empty or tearful.
- Diminished interest or feeling no pleasure in all - or almost all - activities most of the day, nearly every day.
- Significant weight loss when not dieting, weight gain, or decrease or increase in appetite nearly every day.
- Insomnia or increased desire to sleep nearly every day.
- Either restlessness or slowed behavior that can be observed by others.
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness, or excessive or inappropriate guilt nearly every day.
- Trouble making decisions, or trouble thinking or concentrating nearly every day.
- Recurrent thoughts of death or suicide, or a suicide attempt.

What can I do if I develop caregiver depression?

If you're experiencing signs or symptoms of caregiver depression, consult your doctor or a mental health provider. Depression isn't something you can simply "snap out of" - and left untreated, depression can lead to various emotional and physical problems. It can also affect the quality of care you're able to provide for your loved one. However, most people who have depression feel better with the help of medication, psychological counseling or other treatment.

What can I do to prevent caregiver depression?

You can take active steps to prevent caregiver depression. For example:

- Reach out for help. Don't wait until you feel overwhelmed to ask for help caring for a loved one. If possible, get your whole family involved in planning and providing care. Seek out respite services and a caregiver support group. A support network can keep you from feeling isolated, depleted and depressed.
- Remember other relationships. Caregiving can take time away from replenishing personal relationships - but showing loved ones and friends you care about them can give you strength and hope.

- Start a journal. Journaling can improve your mood by allowing you to express pain, anger, fear or other emotions.
- Take time for yourself. Participate in activities that allow you to relax and have fun. Go to a movie, watch a ballgame, or attend a birthday party or religious gathering. Physical activity and meditation also can help reduce stress.
- Stay positive. Caregiving allows you to give something back and make a difference in your loved one's life. Caregiving might also have spiritual meaning for you. Focus on these positive aspects of caregiving to help prevent depression.

Remember, if you think you're depressed, seek help. Proper treatment can help you feel your best.

Source: Reprinted from the MayoClinic.com article "Caregiver depression: prevention counts" (http://www.mayoclinic.com/health/caregiver-depression/MY01264)

Caregiver Grief, Mourning and Guilt

It's normal to feel loss when you care about someone who has Alzheimer's disease. It's also normal to feel guilty, abandoned and angry. It's important to acknowledge these emotions and know that you may start to experience them as soon as you learn of the diagnosis.

Alzheimer's gradually changes the way you relate to the person you know and love. As this happens, you'll mourn him or her and may experience the stages of grieving: denial, anger, guilt, sadness and acceptance. These stages of grief don't happen neatly in order. You'll move in and out of different stages as time goes on. Some common experiences in the grieving process include:

Denial

- Hoping that the person is not ill.
- Expecting the person to get better.
- Convincing yourself that the person hasn't changed.
- Attempting to normalize problematic behaviors.

Anger

- Being frustrated with the person.
- Resenting the demands of caregiving.
- Resenting family members who cannot or will not help provide care.
- Feeling abandoned.

Guilt

- Wondering if you did something to cause the illness.
- Regretting your actions after the diagnosis.
- Feeling bad because you're still able to enjoy life.
- Feeling that you've failed if, for example, you can't care for the person with dementia at home.
- Having negative thoughts about the person or wishing that he or she would go away or even wish he or she would die.
- Regretting things about your relationship before the diagnosis.
- Having unrealistic expectations of yourself, with thoughts such as: "I should have done..." "I must do everything for him or her." "I must visit him or her every day."

Sadness

- Feeling overwhelmed by loss.
- Crying periodically.
- Withdrawing from social activities or needing to connect more frequently with others.
- Withholding your emotions or displaying them more openly than usual

Respite: The Circle of Care

By: Jan Sturges, M.Ed, LPC
Caregiver Consortium

One of the most important "life preservers" for a caregiver is respite care. Temporary relief from caregiving is not only an opportunity to rejuvenate yourself as a caregiver, but a chance to refresh the relationship between you and the person receiving care. Sometimes a little distance does make the heart grow fonder. When you take care of yourself, you are better able to help the person needing your love and support. Caring for self, caring for another - this is the reciprocal circle of care.

According to the National Alliance for Caregiving and AARP, caregiving is being provided for someone who is ill, disabled or aged in almost one in three American households (about 66 million caregivers in 2012). Of those caregivers, 44 million are caring for someone 50 years and older, and 15 million of them are responsible for someone with Alzheimer's disease or another dementia. Fourteen percent of caregivers also care for a child under age 18, and must juggle competing responsibilities between elder care and childcare. In addition, one in six full or part-time working Americans are caregivers, with the added responsibility of work-related tasks to accomplish.

At least one third of caregivers report an increase in their own health problems as well as feeling depressed and socially isolated. If you don't take care of yourself properly, you are taking the risk that you won't be there for your loved ones when they need you the most.

The responsibility of being a caregiver is often all encompassing for people who are caring for a loved one at home, especially if that person is confused or has dementia. When you have a role in the ultimate well-being of another person, your interactions affect both of you at every level - mental, emotional, physical and spiritual regardless of the intensity of care you are providing. Caregiving has a negative impact when the caregiver does not see light at the end of the tunnel and becomes exhausted, overwhelmed and resentful. When you begin to feel this way, it's time to arrange for respite care services. In fact, the best time to think about respite care is before you get to this point! What's even better? Arrange for respite care on a regular basis so you can plan ahead, have something to look forward to, and help your loved one adjust to having other people help out.

What is Respite Care?

The dictionary definition of respite is a temporary period of time for rest and relief. From a caregiving point of view, respite care means finding other qualified people to care for the person who depends upon you so that you can take personal time for yourself or focus on other home or work-related tasks. This might mean that you spend a few hours, or even a few days, away from home in order to restore your own sense of well-being. People are higher functioning when they are relaxed. And, the two timeless maxims of stress management are:

- It is physiologically impossible for your body to be under stress and relaxed at the same time. The more you practice "personal respite," the calmer you will be, and the less impact stress will have on your long-term health.

- You can improve your mental and emotional stamina by returning your body to a brief physiological “state of calm” several times throughout the day. Deep breathing, a short walk, relaxation exercises, journaling, reading, listening to music and other distracting activities will restore the mind/body connection. Recreation means to “re-create.” How creative can you be in the midst of your caregiving experience to give yourself a break?

There are two ways to arrange for respite care by others:

- In-home care, which means that the caregiver arranges for a relative, friend or paid caregiver to come to the house while the caregiver runs errands, goes to medical appointments or participates in pleasurable activities.
- Care for the dependent person at a qualified 24-hours-a-day extended care facility, or adult care home where the person needing care is admitted for a short period of time ranging from a few days to a week or two.

According to the Caregiver Specialists at the Pima Council on Aging, the goals of respite programs of any kind are to:

- Prevent caregiver burnout
- Support the integrity of the family’s lifestyle as much as possible
- Enable the person needing care to live at home for as long as possible

Caregivers that are intentional about scheduling respite care of any type can vastly improve the quality of the caregiving experience.

Why Don’t More Caregivers Use Respite Care?

Many caregivers see themselves as a spouse, son, daughter, sibling, friend or neighbor of someone who needs help, not a “caregiver.” In other words, they see themselves in relationship with the person who needs them. The term “caregiver” may seem too formal. But the necessities of caregiving are more demanding and pervasive, and add an entirely different dimension to the original relationship. The Caregiver Specialists at Pima Council on Aging indicate that there are several reasons caregivers may not seek respite care:

- Personal, family and cultural values that preclude people from getting additional help from non-family members.
- Guilt about “leaving the loved one behind” to do something without them.
- Fear about safety - Will the person or facility providing respite care be qualified, trustworthy and treat the loved one with compassion? This is particularly pertinent if the loved one is confused or immobile.
- Inability to be self-nurturing after taking care of someone else for so long.
- Cost - Caregivers and families with limited funds are often unaware that they may be eligible for respite services at a reduced rate.

Suggestions for Respite Activities

You have finally arranged for respite care. Now what do you do? (It might be hard to remember what you used to do for fun before you were a caregiver.)

- Get some sleep!
- Go for a walk, go to the gym, play your favorite sport.
- Spend time with a friend (one who is supportive and understands your situation).
- Go out for a meal.
- Do some gardening; spend time in nature.
- Start a hobby or rekindle an old one.
- Read a book or magazine.
- Create something artistic - draw, write, play an instrument, sing.
- Attend worship services, and spend time with people who practice the same faith you do.
- Write letters or send emails to friends.
- Follow up with medical appointments.
- Buy something nice for yourself.

Respite Care Produces Positive Results

Respite care can never replace your value as a caregiver. It can only augment, support and strengthen the circle of care and improve the quality of the caregiving relationship. We treat others as we treat ourselves. When you respect yourself enough to be self-nurturing, you will honor and nurture your loved one as well. Here are some of the gains achieved from respite care:

- Stress and resentment reduction
- Improvement in your general health
- Renewed understanding and perspective about caregiving
- Expanded social contact for both you and your loved one
- Opportunity for the person you are helping to give something back to you by accepting help from someone else (if he or she is cognitively able to understand)
- Prolonged capacity over time to care for your loved one

So, protect your loved one by protecting yourself. The best formula for enhancing the caregiver relationship is to schedule respite care on a consistent basis at intervals that are comfortable for you so that the routine becomes comfortable for everyone involved. Remember what the flight attendant says when they talk about the oxygen mask at the beginning of every flight? “If the oxygen mask drops down, make sure you put yours on first before you put it on someone else who needs it.” Respite care is like oxygen. Inhale deeply, and relax.

Selected Caregiving Statistics

Compiled by: Julie Bubul, MSW

Caregiving Population

1. More than **65 million people**, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one. [1]
2. Seven in 10 caregivers are non-Hispanic White (72%), 13% are African-American, and 2% each are Hispanic or Asian-American. Six in ten caregivers are married (58%). Caregivers are predominantly female (66%). They are 48 years of age, on average. One third take care of two or more people (34%). [1]
3. A large majority of caregivers provide care for a relative. More than 37% have children or grandchildren under 18 years old living with them. [1]
4. Caregiving is particularly time-intensive for those who live with their care recipient (39.3 hours/ week) and those caring for a child under the age of 18 (29.7 hours/week). [1]

Women and Caregiving

1. Female caregivers spend more time providing care than men do, on average (21.9 vs. 17.4 hours/ week). [1]
2. Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income (SSI). [4]
3. Stress at home appears to affect younger female employees most, with over 20% of caregiving women ages 18 to 39 reporting they are “almost always” stressed at home. In non-caregiving employees of the same age, only 11% report such a level of stress. [7]
4. More women than men are caregivers: an estimated 66% of caregivers are female. One-third (34%) take care of two or more people, and the average age of a female caregiver is 48. [1]
5. Other studies have found that 36% of women caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting and dressing) when compared with 24% for their male counterparts, who are more likely to help with finances, arrange care, and other less burdensome tasks. [1]

Caregiving Economic Statistics

1. The value of the services family caregivers provide for “free,” when caring for older adults, is estimated to be **$450 billion** a year. That is more than total Medicaid spending in 2009, including both federal and state contributions for both health care and Long-Term Services and Supports ($361 billion).
2. 47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings. [3]
3. The average family caregiver of someone 50 years or older spent $5,531 per year on out of pocket caregiving expenses in 2007 which was more than 10% of the median income for a family caregiver that year. [5]

Impact on Family Caregiver’s Health

1. 23% of family caregivers caring for loved ones for 5 years or more report their health is fair/poor. [1]

2. Nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should and 55% say they skip doctor appointments for themselves. 63% of caregivers report having poorer eating habits than non-caregivers and 58% indicate worse exercise habits than before caregiving responsibilities. [2]
3. 40% to 70% of family caregivers have clinically significant symptoms of depression with approximately a quarter to half of these caregivers meeting the diagnostic criteria for major depression. [6]

Caregiving and Work

1. 73% of family caregivers who care for someone over the age of 18 either work or have worked while providing care; 66% have had to make some adjustments to their work life, from reporting late to work to giving up work entirely; and 1 in 5 family caregivers have had to take a leave of absence. [1]
2. **American businesses can lose as much as $34 billion** each year due to employees' need to care for loved ones 50 years of age and older. [7]

Caregiving and Health Care

1. Employees providing eldercare were more likely to report fair or poor health, and are more likely to report depression, diabetes, hypertension, or pulmonary disease. [7]
2. Employees providing eldercare were more likely to report fair or poor health in general. They were significantly more likely to report depression, diabetes, hypertension, or pulmonary disease regardless of age, gender, and work type. [7]

Caregiver Self-Awareness

1. Over 90% of family caregivers become more proactive about seeking resources and skills they need to assist their care recipient after they have self-identified. [8]
2. 83% of self-identified family caregivers believe their self-awareness led to increased confidence when talking to healthcare professionals about their loved one's care. [8]

Sources

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8. National Family Caregivers Association, Survey of Self-Identified Family Caregivers, 2001.

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 (ALTCS) 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.

Pathfinder: Informed Care Planning FAQs *Revised 12/2013*

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

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.

FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

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

AARP®
Real Possibilities

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 you 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 Arkins, 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

PCOA
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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.

Section 3

LGBT Information and Resources

LGBT Alzheimer's Information & Services

Many lesbian, gay, bisexual and transgender (LGBT) people have experienced difficult and alienating relationships with family, friends, employers and service providers. Some have felt the need to move away from their families of origin, to stay in the closet or to distance themselves from discriminating and prejudiced situations. Yet, LGBT people are more likely to become caregiver for a partner, friend or biological family member. While caregiving can be rewarding, it can also be isolating. This topic sheet will help you navigate community resources and options for support.

Resources for LGBT Caregivers

As a caregiver of someone with Alzheimer's disease, you will face challenges during your journey. These challenges may be common among caregivers of they may be singular to you and your situation. As an LGBT caregiver, you may also have additional considerations or concerns.

Learn More About Alzheimer's Disease

Signs of Alzheimer's disease may appear gradually. It can be easy to explain away changing or unusual behavior as signs of aging when a loved one seems physically healthy. However, it's imperative to consult a doctor or health professional when you see changes in memory, mood or behavior. To learn more about the signs of Alzheimer's disease, visit **alz.org/10signs**.

Access Quality Health Care

LGBT individuals may access routine health care less often than other individuals for fear of inadequate treatment or discrimination. It is important to seek supportive health care that will make you and the individual with Alzheimer's feel comfortable. You may want to seek a medical provider that is sensitive to the LGBT community. Check for referrals to providers from the Gay and Lesbian Medical Association or an LGBT community center in your area.

Connect to Community Resources

The Alzheimer's Association provides information and resources, as well as a number of programs and services to caregivers. You can find out more information on these through our website, **alz.org/dsw**, or by calling us at **800.272.3900**.

Seek Help

Caring for an individual with Alzheimer's can be isolating and lonely. Don't be afraid to seek help from family, friends, and neighbors – and tell them exactly what to do to help.

Visit the Alzheimer's Association Caregiver Center at alz.org/care and tap into the tools available through the Care Team Calendar. This interactive scheduling tool allows friends, family members and neighbors to sign up for caregiving responsibilities – so you get the help you need, when you need it.

Share your experiences with other caregivers facing similar challenges at ALZConnected (**www.alzconnected.org**), an online community where people with Alzheimer's and their caregivers can ask questions, connect with others and find support.

For additional support, call the Alzheimer's Association 24-hours a day at **800.272.3900** and speak with a care consultant who can offer information and support.

Take Good Care of Yourself

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, changes in appetite). Note your symptoms and use relaxation techniques such as yoga or meditation to alleviate them. Watch your diet, exercise and get plenty of rest. Staying healthy will help you be a better caregiver.

To get a tailored list of resources to help, take the Alzheimer's Association Caregiver Stress Check at **alz.org/stresscheck**.

Plan for the Future

It is important for the individual with Alzheimer's to have legal and financial documents in place to establish his or her wishes for care as the disease progresses. Medical and financial powers of attorney and hospital visitation authorizations are best filed in advance while the person is still able to make decisions. In addition, as a caregiver, you should complete legal documents to ensure the individual with Alzheimer's will be cared for should something happen to you. For more information, contact the Desert Southwest Chapter at **800.272.3900**.

Balance Dual Caregiving Roles

It is common for LGBT caregivers to care for their partner and for another friend or family member. It can be difficult to attend to your own physical, emotional and social well-being while providing care to multiple individuals. The Alzheimer's Association can assist you with information and referrals to community resources that can provide support and care for you and your loved ones.

Making Decisions About Long-Term and End-of-Life Care

Long-term care encompasses many types of care situations, ranging from independent living to a variety of assisted living options. The decision to move a loved one into an assisted living facility can be emotional and difficult for anyone to consider. The Alzheimer's Association can help with information on facilities and options for care.

When facing a fatal disease such as Alzheimer's, it is essential for LGBT individuals to have advance directives in place. With advance planning, you can ensure that the individual with Alzheimer's will have optimum care and that you will have the level of access and authority desired by you both.

Consider seeking hospice care to ensure the comfort of the individual with Alzheimer's and to gain emotional support. Contact the Desert Southwest Chapter for information on counseling and hospice agencies in the area.

Disclosing Your Sexuality

You may worry that service providers will respond negatively to your LGBT identity. Perhaps you don't feel it necessary to disclose your sexual orientation or identity. Remember to trust yourself and make sure you are comfortable with what you share. To help with any challenges you face during your caregiving journey, the Alzheimer's Association is available 24/7 through our Helpline at **800.272.3900** to provide you with assistance, information and resources.

Donald W. Reynolds Foundation, the Arizona Geriatric Education Center, and the Arizona Center on Aging

August 2011

ELDER CARE

A Resource for Interprofessional Providers

LGBT Older Adults in Long-Term Care Facilities

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Following decades of experience with discrimination and social stigma, the community of Lesbian, Gay, Bisexual, and Transgender (LGBT) older adults and their loved ones experience a multitude of unique concerns when contemplating placement in long-term care facilities. Administrators, staff, and clinicians in long-term care facilities may not be adequately trained to address LGBT fears and concerns. Facilities may provide care that compromises the health status of LGBT older adults, increases their sense of vulnerability, and lowers satisfaction with peer and staff interactions. Thus, it is important to improve the quality of long-term care for LGBT older adults. Recommendations for improvement are discussed in this issue of Elder Care.

Assessing Readiness to Care for LGBT Older Adults

Although many long-term care facilities may genuinely want to admit LGBT older adults, substantial transformations need to be in place before those adults, their loved ones, and the clinicians wanting to refer them, can be assured that there will be "no problems." These transformations should be visible to prospective LGBT residents (e.g., explicit and positive LGBT pictures and language on websites, brochures, and forms), and evident in staff training and development. It is recommended that facilities assess their readiness to care for LGBT residents (Table on next page), hire external consultants and resources as needed, and highlight key aspects of LGBT culture and history, outlined below, through ongoing training for all employees.

Understanding LGBT Culture and History

Coming Out The first key aspect of LGBT culture and history is the variation and nuances in "Coming Out." For LGBT older than the Baby Boomer cohort, safety and survival were closely linked with clandestine social gatherings prior to the 1970s Gay Liberation Movement. Invisibility and silence were adaptive responses to laws, attacks, and pervasive discrimination enacted against LGBT communities.

Long-term care facilities must offer safe and welcoming environments. Pressures to come out or concerns of being "outed" may increase a sense of vulnerability to maltreatment. LGBT may isolate or defer medical care if environments seem dangerous. Facilities are advised to view coming out as a process vs. an event, with disclosures likely expressed over time through stories and pictures rather than overt use of LGBT language.

Families of Choice Prejudice and negative attitudes do not occur only outside homes. Rather, countless LGBT adults suffer temporary or permanent estrangement from their families of origin. The LGBT community has created important friendship networks offering a strong sense of belonging and mutual support over the lifespan; these networks are termed "families of choice." It is highly recommended that long-term care facilities structure family events and care planning meetings to include LGBT families of choice.

Partners Furthermore, partners of LGBT residents may feel unwelcome or invisible at long-term care facilities. For example, LGBT couples may not be allowed to cohabitate at some facilities and care giving groups may not be attentive to LGBT partners. Facilities that eliminate such rules may simultaneously eliminate some of the marginalization experienced by LGBT partners.

One Size Does Not Fit All The LGBT community is a diverse group. For example, there are differences in the life experiences and expectations among the younger-old and oldest-old LGBT. There are also important considerations for LGBT with additional minority identities involving race, ethnicity, socio-economic status, gender, and acculturation. Religious/spiritual beliefs particularly merit attention in LGBT long term care. Administrators, staff, and clinicians add further to the mix of cultural differences. To facilitate optimal care, facilities should

TIPS FOR LONG-TERM CARE FACILITIES PROVIDNG CARE FOR LGBT OLDER ADULTS

- Assess overall readiness to care for LGBT in welcoming and safe environments that recognize LGBT history, culture, challenges, and strengths.
- Understand variations and nuances in the "coming out" processes for LGBT older adults.
- Honor LGBT partners and families of choice.
- Respect the diversity within the LGBT community.
- Know protections and legal rights for LGBT residents in long-term care facilities.

Health and Long-Term Care Resources on LGBT Aging

Human Rights Campaign: www.hrc.org
Includes Healthcare Equality Index

Project Visibility: www.bouldercounty.org/family/seniors/pages/projvis.aspx

General Resources on LGBT Aging

Diverse Elders Coalition
www.diverseelders.org

Intersex Society of North America
www.isna.org

Lambda Legal
www.lambdalegal.org/search/node/aging

National Center for Lesbian Rights
www.nclrights.org

National Center for Transgender Equality
www.transequality.org

National Resource Center on LGBT Aging
www.lgbtagingcenter.org

National Gay & Lesbian Task Force
www.ngltf.org/our_work/public_policy/lgbt_initiative

Services and Advocacy for LGBT Elders (SAGE)
www.sageusa.org

Southern Arizona Gender Alliance (SAGA)
www.sagatucson.org/wp

Williams Institute
www.williamsinstitute.law.ucla.edu/category/research/international

World Professional Organization for Transgender Health (WPATH)
www.wpath.org

Source: Linda Travis, Psy.D., Argosy University, College of Psychology and Behavioral Sciences

Section 4

In-Home Care

PCOA
PIMA COUNCIL ON AGING
Advocacy, Action, Assistance

Managing Care Helpers in the Home

Helping older care recipients or friends prepare, supervise and plan for paid and/or volunteer help in the home

There may come a time when your care recipient requires more assistance in the home than family and friends can provide. Families usually struggle with the decision to hire outside help and feel guilty about not being able to provide all the needed care themselves. Often caregivers jeopardize their own health and wellbeing by not bringing in outside help until they are at the breaking point. Arranging outside help can provide enormous relief to the family caregiver and allow that caregiver to continue caregiving for a longer period. The wellbeing of the person needing care is also often improved through the increased social stimulation provided by the new caregiver and the improved mood of the family member who has some "time off." When possible, the decision to hire outside help should be made with the participation of your care recipient. However, if your care recipient is unable to comprehend the extent of his or her limitations or has unreasonable expectations about your availability or ability to provide care, then you may have to make the decision to hire outside help without depending on his or her participation.

After hiring a paid caregiver or arranging for other help in the home, you and your care recipient will need to supervise the care being provided.

Frequently Asked Questions about Managing Care Helpers

What should my care recipient and I expect to gain from having paid or volunteer help come into the home?

You should start with having realistic expectations about what services can and cannot be provided. You may have to train your care helper to perform tasks the way you or your care recipient likes to have them done. When you hire help through an agency, be aware that the same care helpers may not be available all the time.

After hiring help at home, you may find that the benefits to your care recipient include:

- The comfort and stimulation of having another person around.
- Different approaches to care leading to favorable results in health, functioning or behavior. For example, your care recipient may readily allow a private caregiver to assist her in bathing whereas she always resists your efforts.
- Improved happiness and well-being.
- Reliable transportation to and from medical appointments and recreational activities.

Benefits to you as the caregiver may include:

- Respite/personal time.
- Reduced stress and peace of mind.
- Learning new caregiving skills.
- A better relationship with your loved one.

What type of information should I gather that would help the caregiver understand my care recipient's needs, likes and dislikes?

Begin by creating a Personal Profile of your care recipient. Write down information in the following areas:

- Emergency Contacts: Keep a list of the names and telephone numbers of family members and friends, treating physicians, pharmacies, health insurance information, emergency medical department preference and poison control.
- Eating/Drinking Preferences: Include dietary restrictions, if any.
- Health: List your care recipient's medical conditions, current treatments, medications, allergies, status of vision, hearing and speech, and the location of advance directives, if applicable.
- Daily Routines: When does your care recipient normally wake, sleep, eat, and exercise? What activities does your care recipient like to engage in? Is there a best time of day or a more difficult time of day to provide care for your care recipient?
- Getting Around: What assistive devices, such as canes, walkers, etc., does your care recipient use? What type of assistance is needed both inside and outside the home? What transportation is best for medical appointments or other outings?
- Assistance or supervision needed with Daily Activities: Does your care recipient need help eating, dressing, grooming, bathing, etc.?

Make a copy of this information for all helpers involved in your care recipient's care.

What questions should I ask to make sure the care helper understands what my care recipient and I need?

Make a list of the things you expect the care helper to do and discuss it with him or her. Identify the tasks that are to be performed and how often each one will be done. For example, how many meals are to be made and when? If you are hiring a professional care helper, keep in mind that he or she has been trained in basic health, home management and personal care and may have valuable insight into your care recipient's needs.

You and your care recipient will need to observe and evaluate the helper. Consider asking yourself the following questions:

- Is the care helper compassionate, professional, calm and proud of his or her work?
- Is the care helper trained in first aid and other appropriate care techniques?
- If your care recipient has a Pre-hospital Medical Care Directive (orange card), does the care

helper understand the terms and is he or she willing to abide by it?

- Is the care helper willing to observe household rules (smoking restrictions, TV or phone use, etc.)?
- Is the care helper willing to do things the way your care recipient wants them done?
- Is the care helper willing to be flexible and do extra tasks if the need arises?
- Are there cultural sensitivities or language abilities that should be addressed?
- What will happen if the care helper is sick or is otherwise unable to arrive at the scheduled time?
- Has the caregiver made adequate plans in case he or she has problems with transportation, childcare, etc.?
- Do arrangements need to be made regarding vacation and holiday coverage and wages?
- How far in advance should the care helper inform you that he or she will be taking time off?
- How much time off does her or she expect to take and how often?
- What arrangements are in place for those times when the care helper won't be there?

Some families choose to hire a care helper privately rather than through an agency. Be aware that as an employer, you are required to complete certain payroll and tax documents including tax withholdings, FICA and other related programs such as unemployment and workman's compensation. In some instances, the care helper will also need to complete an I-9 form for immigration purposes. For a fee, independent accountants or local accounting firms will assist you and make sure you have completed all the required documents to protect you as the employer and the care helper as the employee.

If you hire a caregiver privately, be sure that you thoroughly check references and complete a criminal background check. Also verify any training or certificates the caregiver presents. Once you have thoroughly screened the caregiver, draw up a contract which clearly delineates all duties, rate of pay, time off, etc.

My care recipient has memory problems. Even though we discussed and agreed upon obtaining help outside the family, my care recipient has probably forgotten and might be resistant to accept help. How do I introduce the care helper to my care recipient?

Arrange to be present when a new care helper arrives at your care recipient's home. This provides an opportunity to observe and evaluate the situation. Has the caregiver received training in caring for persons with memory problems? Is the helper pleasant, professional, and sociable? Is your care recipient tearful, uneasy or in need of reassurance?

Many times a new person or activity is scary and threatening for persons with memory disorders. Inform care helpers about your care recipient's memory problems prior to their arrival and discuss possible approaches to be used for introductions so that both your care recipient and care helper may feel comfortable and at ease. For instance, introduce new home care workers as people who are there to help around the house, not to specifically assist the person who has memory problems.

How can my care recipient and I communicate with the care helper to get what we want without making the care helper defensive or negative?

If you are unhappy with the care helper's performance or behavior, or if you question his or her knowledge and skills, speak to the person immediately.

The following are suggestions for communicating your concerns effectively:

- Make sure your message is clearly stated.
- Don't use an accusing tone. Use phrases such as: "How do you think we can correct or change whatever is wrong?" or "I would feel better if we tried it this way."
- Try to put the care helper at ease. Encourage the person to talk. Create an environment that supports good communication.
- Don't jump to conclusions. Avoid making assumptions about what the care helper is going to say.

What are some of the warning signs that may suggest potential problems of exploitation, abuse or neglect?

- Does the care helper prevent family or friends from visiting your care recipient? Is the care helper isolating your loved one from prying eyes?
- Does the care helper do all the talking? Does he or she make decisions for your care recipient?
- Has the care helper invited his or her friends or family into the home or used your care recipient's car without permission?
- Has your care recipient's personality changed since the care helper has been hired? Does your loved one appear afraid?
- Are there checks missing or irregularities in banking statements? In the case of checkbooks, look for missing checks in the back of the checkbook or in unused checkbooks.

These are all signs of potential abuse or exploitation. If you suspect your care recipient is being abused, neglected, and/or financially exploited by a care helper, report your concerns to the care helper's employer. If you privately employ the care helper, report the matter online to Arizona Adult Protective Services, www.azdes.gov/daas/aps. However, if there is a clear indication of abuse, neglect and/or exploitation, fire the care helper and immediately report the crime to Arizona Adult Protective Services.

Caregiver Tips for Managing Home Care Helpers

- Remove or lock up all valuables (jewelry, artwork, cameras, etc.) as well as any cash, checkbooks and bank statements.
- Secure all mail. The care helper should not have access to important mail, such as pension or social security checks and credit card solicitations. You may want to consider renting a post office box or having mail forwarded to your address to make sure your care recipient's mail is secure.
- If the care helper will be shopping for your care recipient, set up a petty cash fund that can be used for that purpose. Require the care helper to return receipts and any change from all purchases so that you can calculate the amount of cash remaining. Never give a care helper a credit card or blank check to use for shopping.

- If the care helper will be driving your care recipient to church, medical appointments or other places, consider doing the following: check your care recipient's insurance policy for information about coverage as a passenger in another person's vehicle. Make a copy of the care helper's current driver's license. You will need this information if there is an accident involving your care recipient's or care helper's car. Also, your insurance agent can use the license to check the care worker's driving record.
- Record on a calendar all scheduled or prearranged visits that will be made to your care recipient's home by friends, maintenance workers, gardeners and other local vendors. You may decide to initiate a rule that requires the care helper to contact you if there is a question about allowing strangers entry into your care recipient's home.
- Care helpers should not be allowed to accept gifts from your care recipient (with perhaps the exception of food items). This protects both your care recipient and the care helper if there is a question about the nature or circumstances surrounding a gift.
- If possible, make "spot checks" of your care recipient's home on the days that the care helpers are scheduled to work. This will provide the opportunity to observe what is happening and whether or not it is appropriate.
- Don't forget about attending to the needs of your care recipient's pets. Outline the specific duties the care helper will be responsible for including daily routines and grooming.
- Set rules about television viewing. The selection of television programs should be for the enjoyment of your care recipient not the care helper.
- Write down instructions or prepare a script describing how the care helper should answer the phone and record messages.

Additional considerations include:

- Will care helpers be allowed to have their own care recipients and friends visit?
- To what extent should care helpers be involved in socializing or participating in activities with your care recipient and his/her friends? Your care recipient may want private time with friends.
- If you hire a care helper who smokes cigarettes, it may be necessary to set limits on the amount of time taken to smoke, and the designated areas (inside and outside) where smoking will be allowed.

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

Employing a Home Care Worker

Self-directed care services offer solutions to some common challenges facing families and individuals dealing with disabilities, chronic conditions, and frailty due to aging. Being able to hire someone you already know helps with trust issues related to bringing a worker into the home, and having the option of hiring someone that speaks your language or understands your culture can determine whether the services being offered are acceptable or not.

Often, self-directed services can be more flexible in scheduling than agency models. But self-directed services aren't for everybody because they demand more involvement by the person being served and/or their caregiver. Before you hire anyone, learn about the practical and legal issues that you may face.

Hire a Company

Usually, if you hire a company to do the work, the company will send over qualified workers and be in charge of paying them. It will also pay employment taxes and have insurance coverage to protect you in case of worker injury or damage to your property. (Ask for proof of this insurance.) Typically, these companies train and do background checks on their employees, but you should confirm both. Hire a worker through an agency If you want a skilled professional but don't know where to look or want one already individually vetted by a third party. You may pay the agency directly, in which case the agency will probably be the actual employer and will cover insurance, handle employment taxes, and pay workers. (You should confirm this with the agency first.) Other agencies may charge you a fee to find you a qualified employee, but you will be the employer and handle these tasks.

Hire an Individual

If you want to screen and select your own service provider, pay and negotiate directly, and direct the person's work, you can hire an individual. However, you may have more obligations as the employer if you elect this route. Typically, a worker hired to perform care services in the home is considered a "domestic worker" by the IRS and most states, and there are specific parameters that determine the level of your obligations as the employer.

Wages and Taxes

If you plan on paying someone at least $1,800 or more in one calendar year or over $1,000 in any one quarter of the calendar year, federal and/or state withholding requirements may apply. If what you pay the worker is less than those amounts, it dramatically reduces the reporting and administrative obligations as an employer. An employer's responsibilities are somewhat complicated because they involve two levels of government, federal and state, as well as several different government agencies. If you are not comfortable handling withholding responsibilities yourself, consider hiring a bookkeeper, accountant or payroll management company to manage these tasks.

Employer Identification Number (EIN)

When you have someone working for you as an employee who earns more than $1,800 per year, you must have an Employer Identification Number (EIN) to be able to report these earnings. You may apply for an EIN online at www.irs.gov/businesses; click “Employer ID Numbers” or you may obtain an EIN immediately by calling 800-829-4933, Monday through Friday, 7:30 a.m. to 5:30 p.m.

As an employer, your tax responsibilities may include withholding, depositing, reporting and paying employment taxes. You must also give certain forms to your employees, and they must give certain forms to you. In addition, there is information that you need to secure for your records and forms that you must complete.

Eligibility to Work in the United States

All employers are required to verify the employment eligibility of new employees by completing the U.S. Citizenship and Immigration Services (USCIS) Employment Eligibility Verification (Form I-9). The Handbook for Employers and Instructions for Completing the Form I-9 (M-274) are available on the USCIS website at www.uscis.gov, select “Working in the U.S.”

E-Verify is an Internet-based system that allows businesses to determine the eligibility of their employees to work in the United States. Use the free E-Verify program at www.uscis.gov under “Verification.”

Employers may contact USCIS at 888-464-4218 with questions regarding the Form 1-9 process or E-Verify.

Employee’s Social Security Number (SSN)

All reportable employees must have a Social Security number. You are required to get each employee’s name and Social Security number and to enter them on Form W-2 if they earned more than $1,800 in that year. (This requirement also applies to resident and nonresident alien employees.)

The Social Security Administration (SSA) offers Social Security verification and quick access to relevant forms and publications at www.socialsecurity.gov/employer/ssnv.htm.

Federal Income Tax, Social Security and Medicare Taxes

As an employer, it is now your responsibility to report payroll information annually to the Social Security Administration and to your employees, but only if they made over $1,800 a year or over $1,000 in any given quarter of the year. Social Security and Medicare taxes pay for benefits that workers and families receive under the Federal Insurance Contributions Act (FICA). Social Security tax pays for benefits under the old-age, survivors and disability insurance part of FICA. Medicare tax pays for benefits under the hospital insurance part of FICA.

You generally must withhold federal income tax from your employees’ wages. You withhold part of Social Security and Medicare taxes from your employees’ wages and you pay a matching amount yourself. All employees must sign a completed and dated IRS Form W-4, “Employee’s Withholding Allowance Certificate.” To review publications and download the W-4 form, visit the IRS website at www.irs.gov, select “Forms & Pubs,” then click “W-4.” Contact the IRS at 800-829-1040 if you have additional questions.

To figure how much to withhold from each wage payment, use the employee's Form W-4 and the methods described in Publication 15, "Employer's Tax Guide" and Publication 15-A, "Employer's Supplemental Tax Guide" at the IRS website, www.irs.gov/businesses, then click "Employment Taxes for Businesses." Call 800-829-3676 or 800-829-1040 if you have additional questions www.irs.gov/publications/p505/index.html. You may find current Federal withholding information at the Internal Revenue Service: www.irs.gov/Businesses/Small-Businesses-&-Self-Employed/Employment-Taxes-2.

Unemployment Tax and Insurance

The Federal Unemployment Tax is part of the federal and state program under the Federal Unemployment Tax Act (FUTA) that pays unemployment compensation to workers who lose their jobs. You report and pay FUTA tax separately from Social Security, Medicare, and withheld income tax. You pay FUTA tax only from your own funds. Employees do not pay this tax or have it withheld from their pay. You report FUTA taxes on the Form 940, "Employer's Annual Federal Unemployment (FUTA) Tax Return." For forms, visit the IRS website at www.irs.gov, and in the search box type "Form 940 and Schedule A (Form 940)." For more information, contact the IRS at 800-829-1040.

Contact the Department of Economic Security for information about registering and submitting unemployment insurance payments.

Arizona Department of Economic Security (ADES)
Unemployment Insurance Information Division
4000 N Central Avenue, Suite 500
Phoenix AZ 85012
602-771-6606; 877-600-2722
Email: uit.status@azdes.gov   website: www.azdes.gov/uitax

Arizona New Hire Reporting

Federal and state law requires employers to report all employees to the Arizona New Hire Reporting Center within 20 days of their hire date whether they are full- time, part-time or temporary. For information on how to report electronically, visit az-newhire.com or call 888-282-2064, ext. 250. Staff members are available to answer questions, discuss reporting options, or provide a demonstration of the website.

Arizona Employee Withholding

You may find current Arizona withholding information at the Arizona Commerce Authority: old.azcommerce.com/doclib/abc/AZEE2013chptr6.pdf. An employer must file a quarterly withholding tax return with the Arizona Department of Revenue (DOR) to report its Arizona withholding tax liability. Refer to the "Arizona Withholding Liability/Payment Schedule" section of the Form A1-QRT instructions, www.azdor.gov/Forms/Withholding.aspx, for withholding payment schedule computation.

Each payday, your employees must receive a statement from you telling them what deductions were made and how many dollars were taken out for each legal purpose. This may be presented in a variety of ways including on the check as a detachable portion or in the form of an envelope with the items printed and spaces for dollar deductions to be filled in.

Arizona's Workers' Compensation Insurance

Under Arizona law, it is mandatory for employers to secure workers' compensation insurance for their employees. Workers' compensation is a "no fault" system in which an injured employee is entitled to receive benefits for an industrial injury, no matter who caused the job-related accident. Employers are required to bear the entire cost of workers' compensation insurance.

Companies may choose to insure their employees by insuring with an authorized insurance carrier of the state or by qualifying as a self-insurer under the rules and regulations of the Industrial Commission. For a listing of these companies, visit the Arizona Department of Insurance website at www.azinsurance.gov, select "Consumers" or contact the Consumer Affairs Division at 602-364-2499 or 800-325-2548. The Industrial Commission of Arizona administers the Workers' Compensation Law. Visit their website at www.ica.state.az.us/Claims/Claims_main.aspx or call 602-542-4661 or 520-628-4661 for more details.

Source: Rewarding Work, Inc. (www.rewardingwork.org) and the Arizona Caregiver Coalition, Inc. (www.azcaregiver.org)

Questions to Ask a Home Care Agency

- How long has the agency been in the community?
- Is the agency bonded and insured?
- Who is responsible for paying payroll taxes, social security, unemployment, and workman's compensation?
- How are caregivers screened? What background checks are done?
- What initial and continuing education is required of caregivers?
- How are their skills evaluated and their credentials checked?
- Have caregivers received specific training in dementia care?
- Are caregivers available with the physical strength and training necessary to perform safe transfers or whatever task is required?
- Are caregivers available with the cultural sensitivity and language skills I need?
- Are caregivers available to meet my specific requirements (e.g., non-smoking, fragrance free, etc.)?
- Does the agency have nondiscrimination policies and provide staff training on cultural competency issues including lesbian, gay, bisexual, and transgender (LGBT) concerns?
- Is the agency Medicare certified? Is my family member eligible for any Medicare covered services? (More information about agencies that are Medicare certified may be found at www.medicare.gov/hhcompare.)
- Will the agency do an assessment to determine required level of care? Is there a charge for this assessment?
- How often are supervisory visits made to the home and who makes them?
- Is someone on call 24 hours a day to respond to emergencies?
- What if my caregiver doesn't arrive on schedule?
- What is the procedure for replacing a scheduled caregiver who is unable to work?
- Can I expect to see the same caregiver each time?
- What if I am not satisfied with the caregiver? Will the agency provide a replacement? How does the agency assess caregiver/client compatibility?
- If I have a complaint, whom do I call? How quickly can I expect a response?
- What is the minimum length of service required? What are the hourly costs?
- Are there different charges at night or on the weekend or for service in outlying areas?
- What could cause rates to increase? When will I be informed of increases?
- What different types of care do they offer: housekeeping, companionship, errands, overnight care, personal care (assistance with bathing)?
- Can caregivers transport clients either in the client's car or their own vehicle? Does mileage cost extra?

Resources for Hiring Caregivers

If you are considering hiring a caregiver for a senior family member or friend, publicly available databases may contain information about the potential caregiver. It would be wise to check the first five sources for information about anyone under consideration for employment.

Furthermore, depending upon the individual's background or training (i.e., certified nursing assistant, physical therapist, etc.), you may also want to check one or more of the licensing databases, listed in the second section below, that contain information about individuals in a specific field or occupation, including whether disciplinary action has been taken.

Even if a person is not listed in any of these databases, that does not guarantee the person is honest and law abiding. We recommend that you verify that the information listed on any web site is current and up-to-date by contacting the relevant agency directly. This is publicly available information which employers of caregivers, and other in home workers, should know exists and utilize as needed.

Updated: August 7, 2012.

Elder Abuse Directories & Licensing Websites That May Contain Information About Prospective Employees	**Summary of Information Available**
Arizona Adult Protective Services Elder Abuse Registry (via written request): (602) 542-4446 or 1 (877) 767-2385 **www.azdes.gov/forms.aspx?menu=100&ekfrm=2712**	Provides names of individuals when allegations have been substantiated against a perpetrator in relation to abuse, neglect, or exploitation of a vulnerable adult.
Arizona Judicial Branch, Trial and Appellate Courts: (602) 452-3300 **www.SupremeCourt.AZ.Gov/PublicAccess**	Provides domestic, civil, and criminal case information in the Arizona Courts System.
Department of Public Safety Sex Offender Information: (602) 255-0611; **az.gov/app/sows/home.xhtml**	Provides names of individuals when allegations have been substantiated in relation to sex crimes.
Arizona Attorney General Elder Abuse Central Registry (submit written request to Consumer Information & Complaints Unit): (602) 542-5763; Outside of the Phoenix Metro Area: (800) 352-8431 **www.azag.gov/consumer/complaintformintro.html**	Provides information about enforcement actions involving abuse or neglect of vulnerable adults.
Office of Inspector General U.S. Department of Health & Human Services: **http://exclusions.oig.hhs.gov/** A phone number is not provided.	Provides names of individuals who are excluded from working for federally funded healthcare programs.

Depending upon a potential caregiver's background or training, you may also want to check the licensing database that contains information about individuals in a specific field or occupation. These databases provide information regarding licensees who have undergone disciplinary action and/or license revocation.

Elder Abuse Directories & Licensing Websites That May Contain Information About Prospective Employees	**Summary of Information Available**
Arizona Board of Behavioral Health Examiners: (602) 542-1882 **www.azbbhe.us/verifications.htm**	Information on (clinical) social workers, counselors, marriage and family therapists, and substance abuse counselors.
Arizona Board of Chiropractic Examiners: (602) 864-5088 **www.azchiroboard.us/ASPSearch.html**	Information on chiropractors.
Arizona Board of Homeopathic and Integrated Medicine Examiners: (602) 542-815 **www.azhomeopathbd.az.gov/phydir.html**	Information about homeopathic and integrated medicine doctors.
Arizona Board of Massage Therapy: (602) 542-8604 **http://massagetherapy.az.gov/directories.asp**	Information about massage therapists.
Arizona Medical Board: (480) 551-2700 or (877) 255-2212 **www.azmd.gov/GLSPages/DoctorSearch.aspx**	Information about doctors, osteopathic physicians and physicians assistants.
Arizona Medical Radiologic Technology Board of Examiners: (602) 255-4845 Disciplinary actions: **https://az.gov/app/mrtbe/**Suspended/revoked licenses: **www.azrra.gov/mrtbe/index.html**	Information about radiologists.
State of Arizona Naturopathic Physicians Medical Board: (602) 542-8242 **www.npbomex.az.gov/directorysearch.asp**	Information about naturopathic physicians.
Arizona Board of Nursing: (602) 771-7800 **www.azbn.gov/onlineverification.aspx**	Information about advanced practice registered nurses, registered nurses, licensed practical nurses and certified nursing assistants.

Elder Abuse Directories & Licensing Websites That May Contain Information About Prospective Employees	**Summary of Information Available**
Arizona Board of Nursing Care Institution Administrators and Assisted Living Facility Managers: (602) 364-2273 **www.aznciaboard.us/**	Information about institution administrators and assisted living facility managers.
Arizona Board of Occupational Therapy: (602) 589- 8352 **www.occupationaltherapyboard.az.gov/licensee directory/default.asp**	Information about occupational therapists and assistants.
Arizona Board of Pharmacy: (602) 771-2727 **www.azpharmacy.gov/disciplines/default.asp**	Information about pharmacists.
Arizona Board of Physical Therapy: (602) 274-0236	Information about physical therapists.
Arizona Board of Psychologist Examiners: (602) 542-8162 **www.psychboard.az.gov/actions.htm**	Information about psychologists.
Arizona Department of Health Services: (Audiologists/Dispensing Audiologists, Hearing Aid Dispensers, and Speech-Language Pathologists): (602) 542-1025 **www.azcarecheck.com/**	Information about audiologists/ dispensing audiologists, hearing aid dispensers and speech-language pathologists.
Arizona Department of Health Services: (602) 364-2536 **www.azcarecheck.com/**	Information about assisted living, long-term care and medical facilities.

This guideline was prepared on behalf of the Task Force Against Senior Abuse in the Office of the Attorney General. The information contained in this guideline is for educational purposes only and does not substitute for the advice of an attorney licensed to practice law in Arizona. Additionally, the Office of the Arizona Attorney General cannot represent individual consumers.

Office of the Arizona Attorney General

Section 5

Living at Home - Safety Tips

Home Safety Hints
To Keep Homes Safe and Secure for Older Adults

Bathroom:
Most falls occur in the bathroom. Implementing a few safeguards will prevent unnecessary accidents. First, use only non-skid mats and carpet on the bathroom floor, as well as applying non-skid strips inside of the tub. Install grab bars around the tub. Make sure you attach them through the tile and to the structural supports in the wall. If either your balance or endurance is poor, think about using a tub seat or tub bench while bathing. Finally, look at where your toiletries are stored. Consider rearranging your cabinets so that commonly used items are within reach.

Bedroom:
Make sure your bedroom is free of clutter with a clear walking path. Always keep a light and phone accessible from the bedside. Can you get in and out of bed easily? Consider adjusting the bed height or installing a bed rail to make the task less strenuous. Use a nightlight for safe nighttime bathroom runs.

Living Room:
Rearrange living room furniture to allow for a clear walking path. Leave extra space if you use a walker. Secure throw rugs, runners, and mats. The Consumer Product Safety Commission estimates that 6800 people, ages 65 and older, are treated in emergency rooms for injuries related to rugs and runners. Apply double-faced adhesive carpet tape, purchase rugs with slip resistant backing or place rubber matting under rugs. Make sure you can safely get up and down from furniture. Consider raising the seat height by adding a cushion or lengthening the legs. Finally, good lighting is essential for fall prevention. Use the maximum wattage bulb allowed.

Kitchen:
Implementing a few home modifications and energy conservation techniques in the kitchen will help prevent falls and back injuries. Consider rearranging your cabinets so that most items can be easily reached. This will limit frequent lifting, bending and carrying. Place small appliances on countertops. Use a chair or stepstool to perform large kitchen jobs. Additional kitchen safety tips include installing a smoke detector, placing a fire extinguisher next to the stove, dating food in refrigerator and providing adequate light.

Source: www.agenet.com/Category_Pages/homesafetyhints

Home Safety Checklist

Home Safety Checklist: The Solutions for Better Aging Home Safety Checklist can be used to identify possible hazards and ineffective use of space in the home. This checklist can help identify ways to make your home safer for independent living.

Entrance:

- Can you enter the house or apartment safely?
- Is a secure handrail present?
- Can you view visitors prior to entry?
- Can you get up and down safely from the sofa and chair?
- Can you open and close the windows?
- Can you manage the television?
- Can you manipulate the light switches?
- Are cords out from beneath carpeting and furniture?

Kitchen:

- Is the doorway accessible?
- Are the appliances in working order?
- Can you manipulate the faucets of the sink?
- Can you open and close the refrigerator and freezer?
- Can you open and close high and low cabinets?
- Is adequate workspace available?
- Can you reach the dishes, pots, silverware, and food supply?
- Can you reach the stove controls?
- Can you manage the stove door?
- Can you reach the outlets?
- Can you safely transport food to eating area?
- Are sharp objects safely stored?
- Are flammables safely stored?
- Do you have a step stool which is stable and in good repair?

Bedroom:

- Is the doorway accessible?
- Can you get up and down safely from the bed?
- Is the light accessible from bed?
- Can you reach the phone?

- Can you reach your clothes in the closet and dresser?
- Is there a clear path to the bathroom?

Bathroom:
Is the doorway accessible?
Can you safely transfer into the tub or shower?
Will a tub bench or tub chair be needed?
Is a bath mat or non-skid strips in place?
Can you safely transfer to the toilet?
Will a safety frame, raised seat or grab bar be needed?
Can you reach the outlets?
Can you manipulate the light switches?
Can you functionally use the sink?

Stairways:
Is a secure handrail present?
Is there adequate illumination?
Is the carpet secure?
Are the steps free of clutter?

General:
Are there working smoke detectors on every floor?
Do you have a carbon monoxide detector?
Are electrical cords free of frays?
Are there any outlets or switches which are unusually warm or hot to touch?
Is there adequate illumination throughout the house?
Are small rugs and runners slip resistant?
Is the house free of pests?
Are the plumbing and utilities working?
Are you able to retrieve the mail safely?
Are emergency phone numbers posted on or near the telephone?
Do you have access to a telephone if you fall?
Are all medicines stored in the containers that they came in and are they clearly marked?

Source: The Home Safety Checklist is reprinted with permission of Solutions for Better Aging, providing comprehensive eldercare solutions including manufacturer-direct access to over 20,000 products at www.betteraging.com and toll free at (888) 405-4242.

Preventing Falls

Don't let a fear of falling keep you from being active. The good news is that there are simple ways you can prevent most falls.

Stay physically active. Regular exercise makes you stronger. Weight-bearing activities, such as walking or climbing stairs, may slow bone loss from osteoporosis. Lower-body strength exercises and balance exercises can help you prevent falls and avoid the disability that may result from falling.

Here are some fall prevention tips from *Go4Life*:

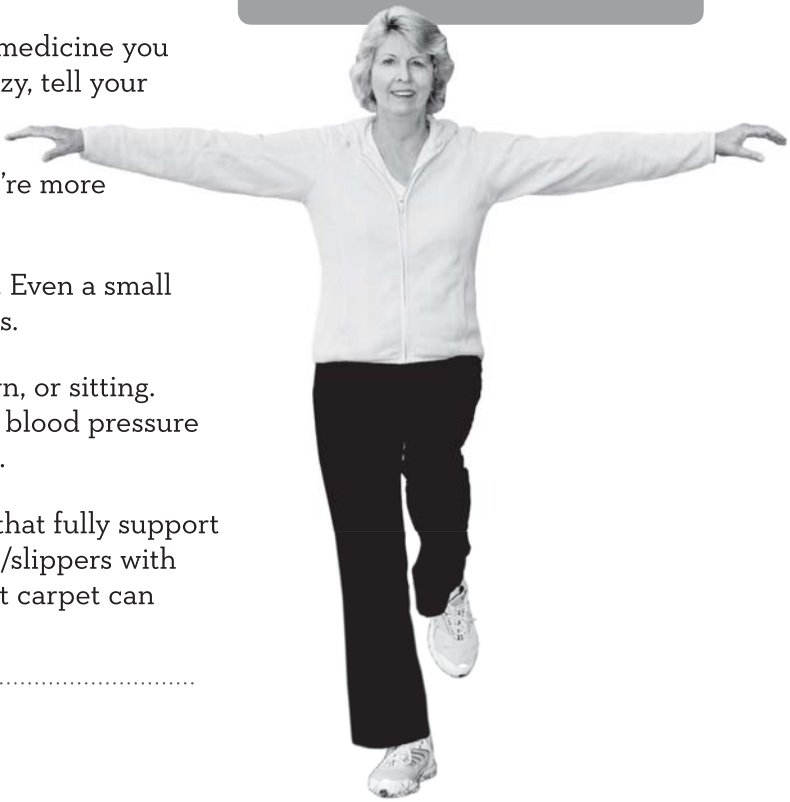
- Have your eyes and hearing tested often. Always wear your glasses when you need them. If you have a hearing aid, be sure it fits well, and wear it.
- Find out about the side effects of any medicine you take. If a drug makes you sleepy or dizzy, tell your doctor or pharmacist.
- Get enough sleep. If you're sleepy, you're more likely to fall.
- Limit the amount of alcohol you drink. Even a small amount can affect balance and reflexes.
- Stand up slowly after eating, lying down, or sitting. Getting up too quickly can cause your blood pressure to drop, which can make you feel faint.
- Wear rubber-soled, low-heeled shoes that fully support your feet. Wearing only socks or shoes/slippers with smooth soles on stairs or floors without carpet can be unsafe.

✓ *Quick Tip*

For more information, read the *Falls and Fractures AgePage.*
www.nia.nih.gov/health

VISIT
www.nia.nih.gov/Go4Life

- **Find sample exercises to help prevent falls.**
- **Print useful tools.**
- **Share your exercise story.**



National Institute on Aging
National Institutes of Health
U.S. Department of Health & Human Services

Fall Proofing Your Home

Six out of every 10 falls happen at home, where we spend much of our time and tend to move around without thinking about our safety. Many of these falls could be prevented by making simple changes. *Go4Life* has the following tips to help you reduce your risk of falling:

- Remove anything that could cause you to trip or slip while walking. Clutter, small furniture, pet bowls, electrical or phone cords, and throw rugs can cause falls.
- Arrange furniture so you have plenty of room to walk freely. Also, remove items from stairs and hallways.
- Secure carpets to the floor and stairs. Use non-slip rugs, or attach rugs to the floor with double-sided tape.
- Avoid wet floors, and clean up spills right away. Use only non-skid wax on your waxed floors.
- Use non-slip items in the bathroom. Put non-slip strips or a rubber mat on the floor of your bathtub or shower.
- Make sure you have enough lighting in each room, on stairs, at entrances, and on outdoor walkways. Use light bulbs that have the highest wattage recommended for the fixture.
- Use the handrails on your stairs. When you carry something up or down the stairs, hold the item in one hand and use the handrail with the other.
- Place a lamp next to your bed along with night lights in the bathroom, hallways, and kitchen. Keep a flashlight by your bed in case the power goes out and you need to get up at night.
- Stay physically active. Lower-body strength and balance exercises can help prevent falls.

✓ *Quick Tip*

For more information, read the *Falls and Fractures AgePage.*
www.nia.nih.gov/health

VISIT

www.nia.nih.gov/Go4Life

- **Read more tips for preventing falls.**
- **Try sample exercises.**
- **Print useful tools.**

National Institute on Aging
National Institutes of Health
U.S. Department of Health & Human Services

Home Modifications and Assistive Devices

What are Home Modifications and Assistive Devices?

Home modifications are changes made to adapt living spaces to meet the needs of people with physical limitations so that they can continue to live independently and safely. These modifications may include adding assistive technology or making structural changes to a home. Modifications can range from something as simple as replacing cabinet doorknobs with pull handles to full-scale construction projects that require installing wheelchair ramps and widening doorways.

Assistive Devices are items or equipment that can help you carry out your daily activities. Examples are walkers, raised toilet seats, reachers and grab bars.

Why Do Seniors Need Home Modifications?

The main benefit of making home modifications is that they promote independence and prevent accidents. According to a recent AARP housing survey, "83% of older Americans want to stay in their current homes for the rest of their lives," but other studies show that most homes are not designed to accommodate the needs of people over age 65. Home modifications and assistive devices can also provide relief and reduce stress on caregivers.

Most older people live in homes that are more than 20 years old. As these buildings get older along with their residents, they may become harder to live in or maintain. A house that was perfectly suitable for a senior at age 55, for example, may have too many stairs or slippery surfaces for a person who is 70 or 80. According to the National Centers for Disease Control and Prevention, each year thousands of older Americans fall at home.

Where Do You Begin?

Before you make home modifications, you or a professional (occupational/physical therapists, case managers, registered nurses, social workers, etc.) should evaluate your current and future needs by going through your home room by room and answering a series of questions to highlight where changes might be made. Several checklists are available to help you conduct this review. The National Resource Center on Supportive Housing and Home Modifications is a good place to start. Go to the center's website at www.homemods.org and click on the link to the "Safety Checklist and Assessment Instrument."

Appliances, Kitchen and Bathrooms

- Are cabinet doorknobs easy to use?
- Are stove controls easy to use and clearly marked?
- Are faucets easy to use?
- Are there grab bars where needed?
- Are all appliances and utensils conveniently and safely located?
- Can the oven and refrigerator be opened easily?
- Can you sit down while working?
- Can you get into and out of the bathtub or shower easily?
- Is the kitchen counter height and depth comfortable for you?

- Is the water temperature regulated to prevent scalding or burning?
- Would you benefit from having convenience items, such as a handheld showerhead, garbage disposal, or trash compactor?

Bathing/Showering

- Place non-skid strips in the tub or shower to provide better traction and to prevent slipping.
- Install a hand-held flexible showerhead to make it easier to wash most of the body, even while sitting.
- Use a shower/tub chair.
- Install grab bars.

Toileting

- Install grab bars or a vertical pole.
- Install a raised toilet seat, high-rise toilet or toilet frame to make it easier to get on and off the toilet.
- Install a night-light.
- Use a bedside commode or bedpan/urinal.

Closets and Storage Spaces

- Are your closets and storage areas conveniently located?
- Are your closet shelves too high?
- Can you reach items in the closet easily?
- Do you have enough storage space?
- Have you gotten the maximum use out of the storage space you have, including saving space with special closet shelf systems and other products?

Doors & Windows

- Are your doors and windows easy to open and close?
- Are your door locks sturdy and easy to operate?
- Are your doors wide enough to accommodate a walker or wheelchair?
- Do your doors have peepholes for viewing?

Getting In/Out of the Home

- Install handrails on both sides of steps.
- Install a ramp or chair elevator.
- Install lever door handles or adapters to round doorknobs.

Driveway & Garages

- Does your garage door have an automatic opener?
- Is your parking space always available?
- Is your parking space close to the entrance of your home?

Electrical Outlets, Switches and Safety Devices

- Are light or power switches easy to turn on and off?
- Are electrical outlets easy to reach?
- Are the electrical outlets properly grounded to prevent shocks?
- Are your extension cords in good condition?
- Can you hear the doorbell in every part of the house?
- Do you have smoke detectors throughout your home?
- Do you have an alarm system?
- Is the telephone readily available for emergencies?
- Would you benefit from having an assistive device to make it easier to hear and talk on the telephone?

Floors

- Are all of the floors in your home on the same level?
- Are steps up and down marked in some way?
- Are all floor surfaces safe and covered with non-slip or non-skid materials?
- Do you have scatter rugs or doormats that could be hazardous?

Hallways, Steps and Stairways

- Are hallways and stairs in good condition?
- Do all of your hallways and stairs have smooth, safe surfaces?
- Do your stairs have steps that are big enough for your whole foot?
- Do you have handrails on both sides of the stairway?
- Are your stair rails wide enough for you to grasp them securely?
- Would you benefit from building a ramp to replace the stairs or steps inside or outside of your home?

Lighting & Ventilation

- Do you have night lights where they are needed?
- Is the lighting in each room sufficient for the use of the room?
- Is the lighting bright enough to ensure safety?
- Is each room well-ventilated with good air circulation?

Once you have explored all the areas of your home that could benefit from remodeling, you might make a list of potential problems and possible solutions.

Where Can I Learn More About Home Modifications?

Mentioned as a resource throughout this fact sheet, the National Resource Center on Supportive Housing and Home Modifications (NRCSHHM) is one of the best sources for more information about home modifications. The center is a major clearinghouse for news on government-assisted housing, assisted-living policies, home modifications for older people, training and education courses. Go to www.homemods.org/directory/index.shtml and view the National Directory of Home Modification and Repair Programs for a listing of what is available in the state where you live.

Source: Eldercare Locator Fact Sheets 7/20/12.
www.eldercare.gov

Preparedness Today: What You Need to Do
Maintaining a Healthy State of Mind for Seniors

"We've proven time and again our ability to survive everything from the Great Depression to world wars and the threat of nuclear holocaust. We've lived through droughts, floods, and all sorts of other natural disasters. We've given birth, supported our families, and stood by our loved ones through personal and financial losses. We are proud, tough and resilient."

"Voices of Wisdom: Seniors Cope with Disasters" videotape, Project COPE, 1992

What can I do to prepare myself now?
These are several things you can do ahead of time, when things are calmer, to get ready to respond to the kinds of events that a natural disaster or an act of terrorism might trigger.

Being mentally and emotionally prepared is the best way to reduce the effects of natural disaster or terrorism. Disaster disrupts our way of life and peace of mind. It can make us feel unsafe and afraid. This may increase feelings of mistrust and prejudice. You may find you react in different ways to stressful events. You may change who you will talk to, trust, or where you travel, or how you spend money. Sometimes feelings of hate towards others arise and lead to violence. This can destroy families and community life.

Although seniors have great strength from life experiences, planning ahead can help decrease the risk of harm in an emergency. When planning ahead ask yourself the following questions:

- Do I tire easily?
- Do I need help to see, hear, or walk?
- Do I need to care for another person?
- Do I take daily medication?

Being mentally and emotionally prepared includes knowing:

- What to expect
- When help is needed
- How to get help

What can I do to prepare myself now?
These are several things you can do ahead of time, when things are calmer, to get ready to respond to the kinds of events that a natural disaster or an act of terrorism might trigger.

If a disaster occurs, how can I best deal with it?
Talking about what happened and sharing your feelings with others you trust or who have lived through similar events can be helpful. It also is important to take care of yourself physically. This includes eating properly, taking your regular medications, and getting a good night's rest. Get back into a normal routine as soon as you can. It helps if you can find meaning in what happened or how you handled things.

- Use the disaster plan you made.
- Find sources of information you can trust.

- Stay informed and follow official directions to protect yourself and others.
- Stay in touch with family, friends, and neighbors, if possible.
- Spend time with family and loved one.
- Even though you need to stay informed, avoid repeatedly watching disturbing events; Watching TV or hearing radio replays of tragic events can increase anxiety and fear.
- Remind yourself of your strengths and how well you have dealt with problems in the past.
- Remind yourself that in time you will feel better.
- Be patient with others and with yourself, take time to relax, and find a quiet place where your can collect your thoughts and feelings.
- Keep up your exercise and good health habits and get plenty of rest.
- Ask for help when you need it.

How will I know if I need more help?

You may try all these ways to feel better and still be unable to get back to your regular routines. You might need outside help if, after several weeks or so, you:

- Still suffer greatly, longer than for other losses and events
- Cannot concentrate or do things you used to enjoy
- Are not able to resume normal roles with your family and friends
- Are you:
    - ➢ Drinking or smoking too much?
    - ➢ Using an excessive amount of prescribed medicines?
    - ➢ Driving too fast or too slowly?
    - ➢ Fighting, hurting, or threatening others?
    - ➢ Having eating or sleeping problems?
    - ➢ Getting physically sick?
    - ➢ Thinking of hurting yourself or someone else?

How do I get help?

Asking for support may sometimes feel uncomfortable; however, seeking the assistance you need can help you cope better. Sources for assistance could include:

- Family Doctor
- Pastoral care counselor
- Licensed counselor or other trained mental health provider
- Health care provider
- Local health center or mental health clinic

How do I prepare for a disaster?

- Develop a plan with family or household members.
- Decide how to stay in touch if something goes wrong .

- Keep a spare pair of eyeglasses and extra medicine handy in case you need to leave your home quickly.
- Learn about preparedness plans in your town.
- Know your neighbors and how to get in touch with them.
- Keep important documents in a safe place with easy access in case you need to leave home.
- Review your options and decide what to do before an emergency happens.
- Know how to get in contact with service agencies you may need, such as the Area Agencies on Aging and the American Red Cross.
- Learn more about what stress does and how to deal with it.

How might I react to an extreme event?

- Shock, numbness, and disbelief
- Fear about personal safety, the safety of others, and pets
- Concern about losing treasured possessions
- Grief for those who died and for losses at earlier times in your life
- Upsetting images, thoughts, and feelings about the event. This can happen suddenly or because something reminds you of the event.
- Anger, short temper, and increased wariness of others. This may include more arguing or fighting.
- Feeling guilty or helpless
- Feeling restless, anxious, uneasy, or worried
- Physical reactions can include headaches and body pains, stomachaches, appetite changes, sleep difficulties, and increased allergic reactions. Chronic health problems can get worse.

For most people, these reactions fade over time and eventually disappear.

Source: Adapted from Preparedness Today – for Seniors – American Red Cross / Centers for Disease Control and Prevention

EMERGENCY PLANNING CHECKLIST
RECOMMENDED TOOL FOR PERSONS WITH MEDICAL NEEDS LIVING AT HOME, THEIR FAMILY MEMBERS, GUARDIANS & CAREGIVERS

Target Date	Date Completed	
		• **Be Responsible and Be Prepared!** By being prepared and staying informed, you can prevent or reduce harm to yourself, your family members and loved ones, or persons for whom you advocate. **Note**: If you are receiving dialysis treatment, please refer to the Centers for Medicare & Medicaid Services (CMS) guide, *Preparing for Emergencies: A Guide for People on Dialysis*, which can be accessed at: www.Medicare.gov/Publications/Pubs/pdf/10150.pdf
		• **Survival Supplies Kit:** You need a survival supply kit that will provide for your needs -- for at least 3 days and up to 10 days. Consider two kits: In one kit put everything you will need to stay where you are and survive on your own for a period of time. The other kit should be a lightweight smaller version that you can take with you if evacuation from your place of residence is necessary. Be sure to bring this kit with you. The kit should be stored in a sturdy, easy-to-use container, and include the following recommended items: ▸ **Basic Supply Kit Items** ✓ Food (label and date, use compact lightweight food, that does not require refrigeration, cooking or preparation; store in plastic bags) ✓ Water (1 gallon per person for each day; include enough for pets and sanitation, label and date, or purchase bottled water) ✓ First aid kit (keep one kit in your home and one in your car) Medications and medical supplies for at least 5 - 7 days (glasses or contact lens, eye wash, hearing aid batteries, etc., as well as over-the-counter supplies, e.g., aspirin, fever/pain relievers, anti-diarrhea medication, emetic, [to induce vomiting], antacids, sterile gauze pads 2-3 inches, sterile roller bandages, adhesive bandages, antiseptic spray, hydrogen peroxide, rubbing alcohol, petroleum jelly, latex gloves, scissors, tweezers, safety pins, etc.). ✓ Wear a medical emblem (bracelet or necklace noting diagnosis, such as “Diabetes,” “Dialysis,” “Hemophilia,” etc.) ✓ Manual can opener, utility knife ✓ Cell phones, phone chargers ✓ Emergency contact names and numbers ✓ Identification (photocopies of identification, driver’s license, Social Security card, Medicare card, other health insurance information, credit cards) ✓ Cash and coins ✓ Sanitation-related items (soap and water, or alcohol-based hand sanitizer, basic personal hygiene items such as toothbrush, toothpaste, denture needs, soap, shampoo, feminine products, wipes, etc., bathroom tissue, facial tissue, paper towels, dust mask, garbage bags, bleach, etc.) ✓ Portable, battery-powered radio or weather radio, plus extra batteries ✓ Flashlight, extra batteries ✓ Blankets, towels, inflatable pillows, air mattresses, sleeping bags

Driving

Driving is a complex activity that requires quick thinking and reactions, as well as good perceptual abilities. For the person with Alzheimer's disease, driving becomes a safety issue. While he or she may not recognize that changes in cognitive and sensory skills impair driving abilities, you and other family members will need to be firm in your efforts to prevent the person from driving when the time comes.

That said, it's important to consider the person's feelings and perceived loss of independence when explaining why he or she can no longer drive. Helping the person with dementia make the decision to stop driving — before you have to force him or her to stop — can help maintain a positive sense of self-esteem.

How dangerous is it?
Previous studies demonstrate that poor driving performance increases with increased dementia severity. However, not all people with Alzheimer's are unsafe drivers at a given point in time. What's more, drivers with dementia are not in more crashes than non-demented elderly drivers, suggesting that dementia should not be the sole justification for suspending driving privileges. Instead, an on-the-road driving test, or other functional test, is the best way to assess driving skills in dementia.

Some state agencies have special drive tests to determine how well a person sees, judges distance and responds to traffic. Ask the person who administers the test to explain the results to you and the person with dementia. If your state does not offer special testing, private assessments (generally fee-for-service) may be available. Your local Alzheimer's Association may be able to provide a list of these programs.

How do you know when the time has come?
There are also a number of steps you can take to assess the person's ability to drive.

1) Look for signs of unsafe driving
Signs of unsafe driving include:

- Forgetting how to locate familiar places
- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Becoming angry or confused while driving

Keep a written record of your observations to share with the person, family members and health care professionals.

2) Learn about your state's driving regulations
In some states, such as California, the physician must report a diagnosis of Alzheimer's to the health department, which then reports it to the department of motor vehicles. That agency then may revoke the person's license. Check with your local Alzheimer's Association for information on driving regulations in your state.

Tips to limit driving

Once it's clear the person with dementia can no longer drive safely, you'll need to get him or her out from behind the wheel as soon as possible. If possible, involve the person with dementia in the decision to stop driving. Explain your concerns about his or her unsafe driving, giving specific examples, and ask the person to voluntarily stop driving. Assure the person that a ride will be available if he or she needs to go somewhere.

Other tips to discourage driving include:

- Transition driving responsibilities to others. Tell the person you can drive, arrange for someone else to drive, or arrange a taxi service or special transportation services for older adults.
- Find ways to reduce the person's need to drive. Have prescription medicines, groceries or meals delivered.
- Solicit the support of others. Ask your physician to advise the person with dementia not to drive. Involving your physician in a family conference on driving is probably more effective than trying by yourself to persuade the person not to drive. Ask the physician to write a letter stating that the person with Alzheimer's must not drive. Or ask the physician to write a prescription that says, "No driving." You can then use the letter or prescription to tell your family member what's been decided.
- Ask a respected family authority figure or your attorney to reinforce the message about not driving. Also ask your insurance agent to provide documentation that the person with dementia will no longer be provided with insurance coverage.
- Experiment with ways to distract the person from driving. Mention that someone else should drive because you're taking a new route, because driving conditions are dangerous, or because he or she is tired and needs to rest. Tell the person he or she deserves a chance to sit back and enjoy the scenery. You may also want to arrange for another person to sit in the back seat to distract the person while someone else drives. If the disease is in an advanced stage, or there is a history of anger and aggressiveness, it's best not to drive alone with the person.
- If the person with dementia wanders, he or she can also wander and get lost by car. Be prepared for a wandering incident and enroll the person in MedicAlert® + Alzheimer's Association Safe Return®, a 24-hour nationwide emergency response service for individuals with Alzheimer's or related dementia that wander or who have a medical emergency. To find out more information or to enroll, contact your local Alzheimer's Association, call 1.888.572.8566 or register online at www.alz.org.
- In the later stages, when the person is no longer able to make decisions, substitute his or her driver's license with a photo identification card. Take no chances. Don't assume that taking away a driver's license will discourage driving. The person may not

remember that he or she no longer has a license to drive or even that he or she needs a license.

What if the person won't stop?
If the person insists on driving, take these steps as a last resort:

- Control access to the car keys. Designate one person who will do all the driving and give that individual exclusive access to the car keys.
- Disable the car. Remove the distributor cap or the battery or starter wire. Ask a mechanic to install a "kill wire" that will prevent the car from starting unless the switch is thrown. Or give the person a set of keys that looks like his or her old set, but that don't work to start the car.
- Consider selling the car. By selling the car, you may be able to save enough in insurance premiums, gas and oil, and maintenance costs to pay for public transportation, including taxicab rides.
- In some states, it might be best to alert the department of motor vehicles. Write a letter directly to the authority and express your concerns, or request that the person's license be revoked. The letter should state that "(the person's full name) is a hazard on the road," and offer the reason (Alzheimer's disease). The state may require a statement form your physician that certifies the person is no longer able to drive.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated July 2007

Warning Signs for Drivers with Dementia

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use this list as an objective way to monitor any changes in driving skills over time. The signs are ranked from minor to serious. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers.

Consider the frequency and severity of incidents. Several minor incidents or an unusual, major incident may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warrant drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.

Driving Behavior Warning Signs – When Noticed, How Often

1. Decrease in confidence while driving
2. Difficulty turning to see when backing up
3. Riding the brake
4. Easily distracted while driving
5. Other drivers often honk horns
6. Incorrect signaling
7. Difficulty parking within a defined space
8. Hitting curbs
9. Scrapes or dents on the car, mailbox or garage
10. Increased agitation or irritation when driving
11. Failure to notice important activity on the side of the road
12. Failure to notice traffic signs
13. Trouble navigating turns
14. Driving at inappropriate speeds
15. Not anticipating potential dangerous situations
16. Uses a “copilot”
17. Bad judgment on making left hand turns
18. Near misses
19. Delayed response to unexpected situations
20. Moving into wrong lane
21. Difficulty maintaining lane position
22. Confusion at exits
23. Ticketed moving violations or warnings
24. Getting lost in familiar places
25. Car accident
26. Failure to stop at stop sign or red light
27. Confusing the gas and brake pedals*
28. Stopping in traffic for no apparent reason*
29. Other signs:

* Stop driving immediately

THE HARTFORD

Section 6

Understanding Alzheimer’s

Alzheimer's Disease

Alzheimer's (AHLZ-high-merz) is a disease of the brain. It destroys brain cells, causing problems with memory, thinking and behavior. It is the most common form of dementia.

It is estimated that there are as many as 5.4 million Americans living with Alzheimer's. This includes 5.2 million people age 65 and over and 200,000 people under age 65 with younger-onset Alzheimer's disease. The number of Americans with Alzheimer's disease and other dementias will grow each year as the proportion of the U.S. population that is over age 65 continues to increase. The number will escalate rapidly in coming years as the baby boom generation ages.

Alzheimer's is not a typical part of aging; it gets worse over time and it is fatal. Today it is the sixth-leading cause of death in the United States. There is currently no cure for Alzheimer's, but new treatments are on the horizon as a result of accelerating insight into the biology of the disease. Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life.

10 Warning Signs of Alzheimer's Disease©

The Alzheimer's Association has developed a checklist of common symptoms to help recognize the warning signs of Alzheimer's disease.

1. Memory changes that disrupt daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion to time and place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

If you or someone you know is experiencing these symptoms, consult a doctor. Every individual may experience one or more of these in different degrees. If you notice any of them, please see a doctor. Early and accurate diagnosis of Alzheimer's disease or other dementias is an important step to getting the right treatment, care and support.

Causes of Alzheimer's disease

In the vast majority of cases, the cause of Alzheimer's disease remains unknown. Most experts agree that Alzheimer's, like other common, chronic conditions, likely develops as a result of multiple factors rather than a single cause. Age is the greatest risk factor for Alzheimer's. Most Americans with Alzheimer's disease are age 65 or older.

A small percentage of Alzheimer cases is caused by rare, genetic variations found in a few hundred families worldwide. In these inherited forms of Alzheimer's, the disease tends to strike younger individuals. When Alzheimer's is first recognized in a person under age 65, this is referred to as "younger-onset Alzheimer's."

How Alzheimer's disease affects the brain

Scientists believe that whatever triggers Alzheimer's begins to damage the brain years before symptoms appear. When symptoms emerge, nerve cells that process, store and retrieve information have already begun to degenerate and die.

Scientists regard two abnormal microscopic structures called "plaques" and "tangles" as the hallmarks of Alzheimer's disease. Amyloid plaques (AM-uh-loyd plaks) are clumps of protein fragments that accumulate between the brain's nerve cells. Tangles are twisted strands of another protein that form inside brain cells. Scientists have not yet determined the exact role that plaques and tangles may play. To learn more about how Alzheimer's affects the brain, see our online Brain Tour: www.alz.org/braintour

Diagnosing Alzheimer's disease

Experts estimate that a doctor experienced in diagnosing Alzheimer's can make a diagnosis with more than 90 percent accuracy. Because there is no single test for Alzheimer's, diagnosis usually involves a thorough medical history and physical examination as well as tests to assess memory and the overall function of the mind and nervous system. The doctor may ask a family member or close friend about any noticeable change in the individual's memory or thinking skills.

Most diagnostic uncertainty arises from occasional difficulty distinguishing Alzheimer's disease from a related dementia. Dementia is a general term for a group of brain disorders that affect memory, judgment, personality and other mental functions. Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of cases.

Vascular dementia, another common form, results from reduced blood flow to the brain's nerve cells. In some cases, Alzheimer's disease and vascular dementia can occur together in a condition called "mixed dementia." Other causes of dementia include frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson's disease. Learn more about related dementias: www.alz.org/relateddementias.

One important goal of the diagnostic workup is to determine whether symptoms may be due to a condition other than Alzheimer's. Depression, medication side effects, certain thyroid conditions, excess use of alcohol and nutritional imbalances are all potentially treatable disorders that may sometimes impair memory or other mental functions. Even if the diagnosis is Alzheimer's disease, timely identification enables individuals to take an active role in treatment decisions and planning for the future.

Treatment and prevention of Alzheimer's disease

Medications approved by the U.S. Food and Drug Administration (FDA) may temporarily delay memory decline and treat Alzheimer symptoms for some individuals, but none of the currently approved drugs is known to stop or prevent the disease. Certain drugs approved to treat other illnesses may sometimes help with the emotional and behavioral symptoms of Alzheimer's.

One important part of treatment is supportive care that helps individuals and their families come to terms with the diagnosis; obtain information and advice about treatment options; and maximize quality of life through the course of the illness.

Many scientists consider the emerging field of prevention one of the most exciting recent developments in dementia research. Some of the most exciting preliminary evidence suggests that strategies for general healthy aging may also help reduce the risk of developing Alzheimer's. These measures include controlling blood pressure, weight and cholesterol levels; exercising both body and mind; eating a brain-healthy diet that is low in fat and includes fruits and vegetables; and staying socially active.

Impact on people living with Alzheimer's disease
Due to changes in the brain, people with Alzheimer's will eventually lose sense of who they are and the ability to care for themselves. The disease affects independence, relationships and the ability to express oneself.

Younger individuals with the disease can also face other issues. If they are employed, they may have to reduce work hours or quit, leaving a gap in the family income. Kids may still be living at home. Insurance and other benefits may be more difficult to get to help pay for care.

Impact on caregivers
Millions of family members are currently facing the enormous physical, emotional and financial impact of caring for a loved one. Seventy percent of people with Alzheimer's live at home, where family and friends provide most of their care and pay for it out of their own pockets.

Impact on society
Alzheimer's takes an enormous toll on society. Total payments from all sources for health and long-term care services for people with Alzheimer's and dementia will amount to $183 billion. People with Alzheimer's and other dementias are high users of healthcare, long-term care and hospice. Total payments for these types of care from all services, including Medicare and Medicaid, are nearly three times higher for older people with Alzheimer's and other dementias than for other older people.

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Updated March 2011

Alzheimer's Disease and Other Dementias

About dementia

Dementia is a general term for a group of brain disorders. Alzheimer's disease is the most common type of dementia, accounting for 60 to 80 percent of cases. This fact sheet briefly discusses Alzheimer's and some other dementias.

All types of dementia involve mental decline that:

- occurred from a higher level (for example, the person didn't always have a poor memory)
- is severe enough to interfere with usual activities and daily life
- affects more than one of the following four core mental abilities
- recent memory (the ability to learn and recall new information)
- language (the ability to write or speak, or to understand written or spoken words)
- visuospatial function (the ability to understand and use symbols, maps, etc., and the brain's ability to translate visual signals into a correct impression of where objects are in space)
- executive function (the ability to plan, reason, solve problems and focus on a task)

Alzheimer's disease

Although symptoms can vary widely, the first problem many people with Alzheimer's notice is forgetfulness severe enough to affect their work, lifelong hobbies or social life. Other symptoms include confusion, trouble with organizing and expressing thoughts, misplacing things, getting lost in familiar places, and changes in personality and behavior.

These symptoms result from damage to the brain's nerve cells. The disease gradually gets worse as more cells are damaged and destroyed. Scientists do not yet know why brain cells malfunction and die, but two prime suspects are abnormal microscopic structures called plaques and tangles. For more detailed information about Alzheimer's disease, please visit our Web site www.alz.org or contact us at 1.800.272.3900.

Mild cognitive impairment (MCI)

In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. The best-studied type of MCI involves a memory problem.

Individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another kind of dementia.

Vascular dementia (VaD)

Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called "post-stroke dementia."

It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be called "multi-infarct dementia."

Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in "steps," where there is a fairly sudden change in function.

People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

Mixed dementia

In mixed dementia, Alzheimer's disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer's and vascular disease.

Decline may follow a pattern similar to either Alzheimer's or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.

Dementia with Lewy bodies (DLB)

In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain's nerve cells. These deposits are called "Lewy bodies" after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson's disease and some cases of Alzheimer's.

Symptoms of DLB include:

- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer's disease
- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls
- Excessive daytime drowsiness
- Visual hallucinations
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not "act out" their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

Parkinson's disease (PD)

Parkinson's is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson's develop dementia in later stages of the disease.

Frontotemporal dementia (FTD)

FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick's disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies.

FTD progresses more quickly than Alzheimer's disease and tends to occur at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or off-color remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells.

Recently, "variant Creutzfeldt-Jakob disease" (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by "mad cow disease." It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve impairment in memory, thinking and reasoning or changes in personality and behavior. Depression or agitation also tend to occur early. Problems with movement may be present from the beginning or appear shortly after the other symptoms. CJD progresses rapidly and is usually fatal within a year.

Normal pressure hydrocephalus (NPH)

Normal pressure hydrocephalus (high-droh-CEFF-a-luss) is another rare disorder in which fluid surrounding the brain and spinal cord is unable to drain normally. The fluid builds up, enlarging the ventricles (fluid-filled chambers) inside the brain. As the chambers expand, they can compress and damage nearby tissue. "Normal pressure" refers to the fact that the spinal fluid pressure often, although not always, falls within the normal range on a spinal tap.

The three chief symptoms of NPH are (1) difficulty walking, (2) loss of bladder control and (3) mental decline, usually involving an overall slowing in understanding and reacting to information. A person's responses are delayed, but they tend to be accurate and appropriate to the situation when they finally come.

NPH can occasionally be treated by surgically inserting a long thin tube called a shunt to drain fluid from the brain to the abdomen. Certain television broadcasts and commercials have portrayed NPH as a highly treatable condition that is often misdiagnosed as Alzheimer's or Parkinson's disease. However, most experts believe it is unlikely that significant numbers of people diagnosed with Alzheimer's or Parkinson's actually have NPH that could be corrected with surgery. NPH is rare, and it looks different from Alzheimer's or Parkinson's to a physician with experience in assessing brain disorders. When shunting surgery is successful, it tends to help more with walking and bladder control than with mental decline.

Huntington's disease (HD)
HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington's has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington's disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

Wernicke-Korsakoff syndrome
Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1). Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:
- confusion, permanent gaps in memory and problems with learning new information
- individuals may have a tendency to "confabulate," or make up information they can't remember
- unsteadiness, weakness and lack of coordination

If the condition is caught early and drinking stops, treatment with high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

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alzheimer's association®

KNOW the 10 SIGNS

EARLY DETECTION MATTERS

Have you noticed any of these warning signs?

Please list any concerns you have and take this sheet with you to the doctor.

Note: This list is for information only and not a substitute for a consultation with a qualified professional.

____1. **Memory loss that disrupts daily life.** One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. **What's typical?** Sometimes forgetting names or appointments, but remembering them later.

____2. **Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. **What's typical?** Making occasional errors when balancing a checkbook.

____3. **Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. **What's typical?** Occasionally needing help to use the settings on a microwave or to record a television show.

____4. **Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. **What's typical?** Getting confused about the day of the week but figuring it out later.

____5. **Trouble understanding visual images and spatial relationships.** For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. **What's typical?** Vision changes related to cataracts.

____6. **New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock"). **What's typical?** Sometimes having trouble finding the right word.

____7. **Misplacing things and losing the ability to retrace steps.** A person with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. **What's typical?** Misplacing things from time to time, such as a pair of glasses or the remote control.

____8. **Decreased or poor judgment.** People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What's typical?** Making a bad decision once in a while.

____9. **Withdrawal from work or social activities.** A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. **What's typical?** Sometimes feeling weary of work, family and social obligations.

____10. **Changes in mood and personality.** The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. **What's typical?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you have questions about any of these warning signs, the Alzheimer’s Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to alz.org/10signs or call 800.272.3900.

alzheimer's association®

Desert Southwest Chapter

Getting a Diagnosis

Memory loss and changes in mood and behavior are some signs that you or a family member may have Alzheimer's disease or a related dementia. If you have noticed these signs, it is important to consider a diagnosis for the following reasons:

- Many things can cause dementia which is a decline in intellectual ability severe enough to interfere with a person's daily routine. Dementias related to depression, drug interaction, malnutrition, B-12 deficiency, and thyroid problems may be reversible.
- Other causes of dementia include strokes, Huntington's disease, and Parkinson's disease. Alzheimer's disease is the most common cause of dementia. It is important to identify the actual cause in order for an individual to receive the proper care.
- An individual who may have Alzheimer's disease may be able to maximize the quality of his or her life by receiving an early diagnosis. It may also help to resolve anxiety of wondering "What's wrong with me?"
- An early diagnosis may allow time to plan for the future. Decisions regarding care, living arrangements, financial and legal issues, and other important issues may be addressed while the individual can still participate fully in making informed decisions.
- Alzheimer's disease is known to strike persons in their 40's and 50's. This "early onset" form of Alzheimer's disease presents unique planning issues for the individual and family members.

THE DIAGNOSTIC PROCESS

There is no one diagnostic test that can detect if a person has Alzheimer's disease. Typically, diagnosis is made by creating a detailed medical history of the person and by reviewing the results of several tests. These include a complete physical and neurological examination, a psychiatric assessment and laboratory tests. Once this testing is completed, a diagnosis of "probable" Alzheimer's disease may be made by process of elimination. However, experienced diagnosticians can be 90-95% certain that their diagnosis is accurate. The process may be handled by a family physician or may involve a diagnostic team of medical professionals, including the primary physician, neurologist (a physician specializing in the nervous system), psychiatrist, psychologist and nursing staff.

The diagnostic process generally takes more than one day and is usually performed on an outpatient basis. It may involve going to several different locations or even to a specialized Alzheimer's diagnostic center. The Alzheimer's Association Desert Southwest Chapter can refer you to physicians and/or diagnostic centers in the community.

Steps in getting a diagnosis usually involve the following:

1. **Medical History Determination**
   The person being tested and family members will be interviewed both individually and together to gather background information on the person's daily functioning, current mental and physical conditions, as well as family medical history.

2. **Mental Status Evaluation**
   During the mental status evaluation, the person's sense of time and place, and ability to remember, understand, communicate and do simple calculations are assessed. The person may be asked questions such as, "What year is it? What day of the week is it? Who is the current president?" The person will also be asked to complete mental exercises, such as spelling a word backwards, writing a sentence, or copying a design. When reviewing the rest results, the physician will consider the individual's overall performance in relation to his or her education background physical condition and occupation.

3. **Physical Examination**
   During the physical exam, the physician will evaluate the individual's nutritional status, blood pressure, pulse and other factors. The physician will also search for the presence of cardiac, vascular, respiratory, liver, kidney and thyroid diseases. Some of these conditions or the combination may cause dementia-like symptoms in some individuals.

4. **Neurological Exam**
   A physician, usually a neurologist, will evaluate the person's nervous system for problems that may signal brain disorders other than Alzheimer's disease. The physician will search for evidence of previous strokes, Parkinson's disease, hydrocephalus (fluid accumulation in the brain), brain tumors, and other illnesses that impair memory and/or thinking. The physician will learn about the health of the brain by testing coordination, muscle tone and strength, eye movement, speech and sensation. For example, the physician will test reflexes by tapping the knee, check the person's ability to sense feeling in their hands and feet, and listen for slurred speech.

5. **Laboratory Tests**
   A variety of tests will be ordered by the physician to help diagnose Alzheimer's disease by ruling out other disorders. Levels of vitamin B-12 and folic acid are measured, as low levels may be associated with dementia. Since very high or low amounts of the thyroid hormones can cause confusion or dementia, levels of the thyroid hormones are measured through a blood test. A physician may also order an EEG (electroencephalogram) to detect abnormal brain wave activity. This test can detect conditions such as epilepsy, which can sometimes cause prolonged, but mild seizures that leave a person in a confused state.

   A CT (computerized tomography) scan, which takes x-ray images of the brain, is also frequently used. The brain is scanned for evidence of tumors, stokes, blood clots and the build up of fluid associated with hydrocephalus. MRI (magnetic resonance imaging) is another brain-imaging technique sometimes used. Other tests may also be recommended but are not usually necessary for the diagnosis. These include PET (positron emission tomography) scans, which shows how different areas of the brain respond when the person is asked to perform different activities, such as reading, listening to music or talking; and SPECT (Single Orton Emission Computed Tomography) scan, which shows blood circulation in the brain.

6. **Psychiatric, Psychological and other Evaluations**
   A psychiatric evaluation can rule out the presence of other illnesses, such as depression, which can result in memory loss similar to dementia of the Alzheimer type. Neuropsychological testing

may also be done to test memory, reasoning, writing, vision-motor coordination and ability to express ideas. These tests may take several hours, and may involve interviews with a psychologist, as well as written tests. These tests provide more in-depth information than the mental status evaluation. Nurses, and occupational, rehabilitation or physical therapists may be called upon to look for problems with memory, reasoning, language and judgment affecting the person's daily functioning.

UNDERSTANDING THE DIAGNOSIS

Once testing is completed, the diagnosing physician or other members of the diagnostic team will review the results of the examination, laboratory tests and other consultation to arrive at the diagnosis. If all test results appear to be consistent with Alzheimer's disease, the clinical diagnosis will be "probable Alzheimer's disease", or "dementia of the Alzheimer type." If the symptoms are not typical, but no other cause is found, the diagnosis will be "possible Alzheimer's disease." Although researchers have made enormous progress in diagnostic testing, the only way to prove Alzheimer's disease is through an autopsy. If a cause of dementia other than Alzheimer's disease is diagnosed, call the Alzheimer's Association, Desert Southwest Chapter at (520) 322-6601 to request a free informational brochure about related causes of dementia.

THE FAMILY'S ROLE IN DIAGNOSIS

While some people with Alzheimer's disease may initiate their own diagnosis and care, for most, it will be up to another family member to alert the physician. Here are some tips that will help you get someone to the physician for an initial evaluation:

- Schedule the appointment for the person.
- Help with transportation to the appointment.
- Read this pamphlet as a family, to gain a better understanding of what to expect during the diagnostic process.
- Contact the Alzheimer's Association Desert Southwest Chapter if you have any questions or concerns.
- Offer to accompany the person during the testing process if he or she is still uneasy about investigating possible Alzheimer's disease.

On the day of the appointment, bring along items such as glasses, hearing aids, devices that help the person walk, a list of all medications the person is taking, and other personal items that might help during diagnostic testing. Be sure the physician has all medical records, insurance and social security information.

PREPARING FOR DIAGNOSTIC TESTS

Once the initial appointment has been made to evaluate a person, the diagnostic team will need certain information to make an accurate diagnosis. Following are questions that you may want to ask regarding the diagnostic process. It may be helpful to start writing down events that occur and any changes in the person's abilities, behavior and personality that cause you to suspect Alzheimer's disease.

Questions You May Be Asked:

- What symptoms have you noticed?
    - Do you have difficulty performing simple tasks?
    - Is there recent memory loss that affects job skills?
    - Have you noticed poor or decreased judgment?
    - Are there other things you've noticed?
- When did symptoms first appear?
- How have the symptoms changed over time?
- Does the individual suffer from other medical conditions?
- Have other family members been diagnosed with Alzheimer's disease?

Questions to Ask Before Diagnosis Testing:

- Which test will be performed?
- Will any of the tests involve pain or discomfort for the individual?
- How long will the test take?
- How long will it take to learn the results of the test?

Questions To Ask If the Diagnosis is Probable Alzheimer's disease:

- What does the diagnosis mean?
- What symptoms can be anticipated next?
- How will they change over time?
- What level of care will be required now and in the future?
- What medical treatment is available?
- What are the risks and effectiveness?
- What changes should be made in the home to make it safer?
- What resources and support services are available in our community?
- Are experimental drug trails available?

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The Alzheimer's Association Desert Southwest Chapter provides programs and services to tens of thousands of families including Helpline – a 24/7 assistance line, MedicAlert®+Safe Return®, Family Care Consultation, Support Groups, Education, Early Stage Programming and Legislative Advocacy. Please, contact us for any more information or assistance, 24 hours a day, seven days a week, at 800.272.3900 or online at www.alz.org/dsw.

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Stages of Alzheimer's Disease

Each individual's experience with Alzheimer's disease is unique. However, there are some changes that are more common or expected. This chart overviews some the more typical changes caregivers may see throughout the disease.

Early Stage (2-4 years leading up to diagnosis)	**Middle Stage** (2-10 years)	**Late Stage** (1-3 years)	**Terminal Stage**
Symptoms: • Moderate memory loss with increased loss of recent events •Difficulty performing familiar tasks •Problems with language •Some difficulty with time and place •Poor or decreased judgment •Difficulty with problem solving • Changes in personality, mood behavior •Anxiety & depression about symptoms •Loss of initiative • Usually independent in daily living activities	**Symptoms:** • Increasing memory loss, confusion or shorter attention span • Problems recognizing friends/family • Disorientation to time, place & situation • More impaired judgment & problem solving skills • Difficulty organizing thoughts, actions and thinking logically • Personality and behavioral changes • May be suspicious, irritable, restless • Loss of impulse control • May see or hear things not present • May develop problems with bathing or receiving physical care from others • Becoming more dependent on others for assistance with physical care and home chores	**Symptoms:** • Severe memory loss • Minimal or no speech • Increased feeding and/or swallowing problems • Knows only self • NO judgment or problems solving skills • Unable to control bladder or bowels • May place items in mouth • May not be able to walk or need maximum amount of assistance to walk • May be prone to infection or skin break down • May have seizures • Dependent for all care needs	**Symptoms:** • Generally has most of late stages symptoms and any of the following symptoms to meet hospice eligibility: ○ (aspiration) pneumonia ○ Bladder infection ○ General infection ○ Bed sores ○ Fever after treating with antibiotics ○ Weight loss and inability to maintain sufficient fluids
Examples: • Forgets things more often and becomes more forgetful as disease progresses • Paying bills/writing checks becomes more difficult and contains errors • Loses things • Arrives at wrong time or place and constantly rechecks calendar • Word finding and language skills become more impaired • Difficulty starting or completing activities • Routine chores become more difficult and take longer to complete • Gets lost or confused especially in new environment • Gets lost driving	**Examples:** • Memory loss becomes more severe • May ask questions over and over • Difficulty with personal care such as bathing, dressing or personal hygiene • Difficulty shopping, preparing meals, caring for home & managing finances • Can't find the right words • Problems with numbers • Suspicious – may accuse spouse of hiding things or infidelity • Loss of impulse control, sloppy manners, may undress at inappropriate times • Sleep disturbance at night – may wake up and wander	**Examples:** • Looks into mirror or talks to own image • Speaks very little or makes no sense • May scream, groan or make grunting sounds (this may indicate pain) • May hold food in mouth or forget to chew or swallow • May start to sleep more	**Examples:** • Bed bound or wheelchair bound • Frequent infections or fever • Unexplained weight loss • Not able to swallow or begins to choke • Person's previously stated views about death and dying are recognized and honored by caregiver(s)
Care Needs: Individuals can generally live alone but may need supervision for driving, taking medications, oversight of finances, and/or housekeeping/lawn care chores	**Care Needs:** Needs 24-hour supervision, structure and routine. May respond to verbal reminders to initiate and/or complete daily living skills	**Care Needs:** Needs 24-hour supervision and total assistance with all care needs. Depending on symptoms, Hospice evaluation can be initiated	**Care Needs:** Needs 24-hour supervision and total assistance for all care needs. Person should qualify for Hospice program

Differences Between Normal Aging and Alzheimer's Disease

- You forget where you parked your car but not that you drive a car
- You forget where you put your keys, but not what the keys are for
- You go into a room and forget why you're there, but not where you are
- You forget people's names, but not their faces
- You sometimes can't find the right word, but don't forget what the word means
- Driving to your friend's house, you inadvertently turn into the shopping center, but your don't lose your way

Basic Principles of Caring for a Person with Memory Loss and Confusion

Tips on Technique
- Set and follow simple routines
- Use distractions
- Encourage independence
- Reassure and praise
- Connect by joining in their make-believe world
- Do not accuse of lying
- Do not personalize remarks
- Do not confront, disagree or argue
- Do simple self-esteem building activities
- Let person maintain control over activities as much as possible
- Give person every opportunity to function at maximum potential
- Do not make unrealistic demands on the person

Minimizing Risks at Home
- Make home simple, safe and familiar
- Reduce unnecessary clutter
- Clear pathways
- Lower water temperature
- Supervise smoking
- Place locks on doors

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Telling Others About an Alzheimer Diagnosis

When you learn that someone you care about has Alzheimer's, you may hesitate to tell the person that he or she has the disease. You may also have a hard time deciding whether to tell family and friends. Once you are emotionally ready to discuss the diagnosis, how will you break the news? Here are some suggestions for talking about the disease with others.

Respect the person's right to know

- You may want to protect the person by withholding information. But your loved one is an adult with the right to know the truth. It can be a relief to hear the diagnosis, especially if the person had suspected he or she had Alzheimer's disease.

- In many cases, people who are diagnosed early are able to participate in important decisions about their healthcare and legal and financial planning.

- While there is no current cure for Alzheimer's, life will not stop with the diagnosis. There are treatments and services that can make life better for everyone.

Plan how to tell the person

- Talk with doctors, social workers and others who work with people who have Alzheimer's to plan an approach for discussing the diagnosis.

- Consider a "family conference" to tell the person about the diagnosis. He or she may not remember the discussion, but may remember that people cared enough to come together. You may need to have more than one meeting to cover the details.

- Shape the discussion to fit the person's emotional state, medical condition and ability to remember and make decisions.

- Pick the best time to talk about the diagnosis. People with Alzheimer's may be more receptive to new information at different times of the day.

- Don't provide too much information at once. Listen carefully to the person. They often signal the amount of information they can deal with through their question and reactions. Later, you can explain the symptoms of Alzheimer's and talk about planning for the future and getting support.

Help the person accept the diagnosis

- The person may not understand the meaning of the diagnosis or may deny it. Accept such reactions and avoid further explanations.
- If they respond well, try providing additional information.
- The person with Alzheimer's may forget the initial discussion but not the emotion involved. If telling them upsets them, hearing additional details may trigger the same reaction later.

- Reassure your loved one. Express your commitment to help and give support. Let the person know that you will do all you can to keep your lives fulfilling.
- Be open to the person's need to talk about the diagnosis and his or her emotions.
- Look for nonverbal signs of sadness, anger or anxiety. Respond with love and reassurance.
- Encourage the person to join a support group for individuals with memory loss. Your local Alzheimer's Association can help you locate a group. To find an Association near you, please call 1.800.272.3900 or go to www.alz.org.

Telling family and friends
An Alzheimer diagnosis doesn't only affect the person receiving it. The lives of family members and friends may also drastically change.

- Be honest with family and friends about the person's diagnosis. Explain that Alzheimer's is a brain disease, not a psychological or emotional disorder.
- Share educational materials from the Alzheimer's Association. The more that people learn about the disease, the more comfortable they may feel around the person.
- Invite family to support groups sponsored by your local Alzheimer's Association.
- Realize that some people may drift out of your life, as they may feel uncomfortable around the person or may not want to help provide care.
- Alzheimer's disease can also impact children and teens. Just as with any family member, be honest about the person's diagnosis with the young people in your life. Encourage them to ask questions.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

Updated September 2007

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Understanding Challenging Behaviors

Alzheimer's disease or a related disorder can cause a person to act in different or unpredictable ways. Some individuals become anxious or aggressive; others repeat certain questions or gestures. These changes can lead to frustration and tension, particularly between the demented person and their caregivers (family, friends and for professionals).

It is important to remember that the person is not acting this way on purpose. Changes in behavior can be caused by:

- Physical discomfort (illness, medication)
- Over stimulation (loud noises, a busy or active environment)
- Unfamiliar surroundings (new places, inability to recognize home)
- Complicated tasks (difficulty with activities or chores)
- Frustrating interactions (inability to communicate effectively)

Whatever the case, be sure to identify the special challenge and consider possible solutions.

First, identify and examine the behavior.

- What is the undesirable behavior? Is it harmful to the individual or others?
- What happened just before the behavior occurred? Did something "trigger" the behavior?
- What happened immediately after the behavior occurred? How did you react?
- Try to answer the following questions: What, where, when, why, and how?

Next, explore potential solutions.

- What are the needs of the person with dementia? Are they being met?
- Can adapting the environment help reduce the difficult behavior?
- How can you change your reaction, or approach to the behavior? Are you responding in a calm and supportive way?

And finally, try different responses in the future.

- Did your new response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

UNDERSTANDING AND RESPONDING TO CHALLENGES

Each person with Alzheimer’s disease or a related disorder is not the same, so the behaviors or changes experienced are also different. Therefore, families and caregivers respond to difficult situations in different ways. Next, we will identify some of the most common challenging behaviors and explore possible ways to respond to them.

REPETITIVE ACTION OR CONVERSATIONS

Persons with Alzheimer’s or a related disorder may do or say something over and over again. They may repeat a word, question or activity. In most cases, they are probably looking for comfort, security and familiarity.

They may also pace or undo what has just been finished. These actions of often harmless for the person with Alzheimer’s disease or a related disorder, but can be stressful for the caregiver and others.

Here are some ways to respond to repetitive behaviors:

- **Look for a reason behind the repetition**. Try to find out if there is a specific cause for the behavior and eliminate it.
- **Respond to the emotion, not the behavior**. Rather than focusing on what they are doing, think about how they are feeling.
- **Turn the action or behavior into an activity**. If they are rubbing a hand across the table, give them a cloth and ask them to help with dusting.
- **Stay calm and be patient**. Reassure them with a calm voice and gentle touch.
- **Answer them**. Give them the answer they’re looking for, even if you have to repeat several times.
- **Engage them in an activity**. They may simply be bored and need something to do. Provide structure and engage them in a pleasant activity.
- **Use memory aids**. If they ask the same questions over again, remind them with notes, clocks, calendars, or photographs.
- **Accept the behavior and work with it**. If it isn’t harmful, let it be and try to find ways to work with it.
- **Consult a physician**. Repetitive behaviors may be a side effect from medication. Talk with the affected person’s physician.

AGGRESSIVE BEHAVIORS

Aggressive behaviors may be verbal (shouting, name-calling) or physical, (hitting, pushing). These behaviors can occur suddenly without an apparent reason, or result from a frustrating situation. Whatever the case, it is important to try to understand what’s causing the person to become angry or upset.

Here are some potential ways to respond:

- **Try to identify the immediate cause**. Think about what happened right before the reaction that may have “triggered” the behavior.

- **Focus on the feelings, not the facts**. Try not to concentrate on specific details; rather, consider emotions. Look for the feelings behind the words.

- **Don’t get angry and upset**. Be positive and reassuring and speak slowly with a soft tone.

- **Limit distractions**. Examine the environment and make adaptations to avoid similar situations in the future.

- **Try a relaxing activity**. Use music, massage or exercise to help sooth the person.

- **Change focus to another activity**. The immediate situation or activity may have unintentionally caused the aggressive response. Try something different.

SUSPICIOUS THOUGHTS

Due to memory loss and confusion, persons with Alzheimer’s disease may see things differently. They may become suspicious of those around them and accuse them of theft, infidelity or other improper behavior. At times, they may also misinterpret what they see and hear.

If this happens:

- **Don’t take offense**. Listen to what’s troubling them and try to understand their reality. Then be reassuring and let them know you care.

- **Don’t argue or try to convince**. Allow them to express their opinions. Agree with their assumptions and acknowledge their thoughts.

- **Offer a simple answer**. Share your thoughts with them, but don’t overwhelm them with lengthy explanations or reasons.

- **Switch his/her attention to another activity**. Try to engage them in an activity or ask them to help with a chore.

- **Duplicate items if lost**. If they’re looking for a specific item, have several available. For example, if someone’s always looking for a wallet, purchase two of the same kind.

RECOGNITION DIFFICULTIES

At times, person with Alzheimer’s disease or a related disorder may not recognize familiar people, places, or things. They may forget relationships, call family members by other names and become confused about where they live. They may also forget the purpose of common items, such as a pen or a fork. These situations can be extremely difficult for caregivers to handle and require much patience and understanding.

Caregivers should:

- **Stay calm**. Although being called by a different name or not being recognized may be quite painful, try not to make your hurt apparent.

- **Reply with a brief explanation**. Don’t overwhelm the person with lengthy statements and reasons. Instead, clarify with a simple explanation.

- **Show photos and other reminders**. Use photographs and other items to remind the person of important relationships and places.

- **Offer corrections as a suggestion**. Avoid explanations that sound like scolding. Try, “I thought it was a spoon” or “I think he is your grandson, Peter.”

- **Try not to take it personally**. Remember, Alzheimer’s disease or other related disorder causes the affected individual to forget. But your support and understanding will always be appreciated.

ANXIOUS OR AGITATED FEELINGS

Persons with Alzheimer’s or other related disorder may feel anxious or agitated at times. They may become restless and need to move around or pace. They may become upset in certain places or focused on specific details. They may also be over-reliant on the caregiver for attention or direction.

If the persons with Alzheimer’s disease or a related disorder becomes anxious or agitated:

- **Listen to their frustration**. Find out what may be causing their anxiety and try to understand.

- **Reassure them**. Use calming phrases and let them know you’re there for them.

- **Involve them in activities**. Try using art, music, or touch to help them relax.

- **Modify the environment**. Decrease noise and distractions or move to another place.

- **Find outlets for their energy**. They may be looking for something to do. Take a walk, play ball or go for a ride whenever possible.

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Compassionate Communication

DON'T

Don't reason.
Don't argue.
Don't confront.

Don't remind them they forget.
Don't question recent memory.
Don't take it personally!

Ooops! You must be kidding.
You mean I can't reason???
Or argue??? Or remind???

DO

Give short, one-sentence explanations.
Repeat instructions or sentences *exactly* the same way.
Allow plenty of time for comprehension.
Eliminate "but" from your vocabulary; substitute "nevertheless".

Agree with them or distract them to a different subject or activity.
Accept the blame when something's wrong (even if it's fantasy).
Leave the room, if necessary, to avoid confrontations.

Respond to the feelings rather than the words.
Be patient and cheerful and reassuring. Go with the flow.
Elevate your lever of generosity and graciousness.

Hmmm…..accept blame?
This is gonna be tough!

REMEMBER

They are *not* crazy or lazy. They are saying normal things, and doing normal things, for an AD patient. If they were doing things, or saying things, to deliberately aggravate you, *they would have a different diagnosis.*

Some days they'll seem normal, but they're *not.* Their reality is now different than yours and *you cannot change them.* You can't control the disease. You can only control *your reaction* to it.

Their disability is memory loss. They cannot remember and *can't remember that they cannot remember.* They'll ask the same question over and over *believing it's the first time they've asked.*

They do not hide things; they *protect* things by putting them in a safe place and then forgetting they've done so. Do not take 'stealing' accusations personally.

They are scared all the time. Each patient reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive, or physically combative. They may even do them all at different times, or alternate between them. Anxiety may compel them to *shadow you* (follow everywhere). They can't remember your reassurances. Keep saying them.

Call the Helpline if you need suggestions on handling challenging situations…in Tucson 520-322-6601 or 800-272-3900

Don’t reason

PWD: “What doctor’s appointment? There’s nothing wrong with me.”

Don’t: (reason) “You’ve been seeing the doctor every three months for the last two years. It’s written on the calendar and I told you about it yesterday and this morning.”

DO: (short explanation) “It’s just a regular check-up.”
(accept blame) “I’m sorry if I forgot to tell you.”

Don’t ask questions of recent memory.

PWD: “Hello, Susie. I see you’ve brought a friend with you.”

Don’t: (question memory) “Hi, Mom. You remember Eric, don’t you? ….What did you do today?

Do: (short explanation) “Hi, Mom. You look wonderful! This is Eric. We work together.”

Don’t argue.

PWD: “I didn’t write this check for $500. Someone at the bank is forging my signature.”

Don’t: (argue) “What? Don’t be silly! The bank wouldn’t be forging your signature.”

DO: (respond to feelings) “That’s a scary thought.”
(reassure) “I’ll make sure they don’t do that.”
(distract) “Would you help me fold the towels?”

Don’t take it personally!

PWD: “Who are you? Where is my husband?”

Don’t: (take it personally) “What do you mean—who’s your husband? I am!”

Do: (go with the flow, reassure) “He’ll be here for dinner.”
(distract) “How about some milk and cookies? Would you like chocolate or oatmeal?”

Don’t confront

PWD: “Nobody’s going to make decisions for *me*. You can go now…and don’t come back!”

Don’t (confront) “I’m not going anywhere and you can’t remember enough to make your own decisions.”

DO: (accept blame or respond to feelings) “I’m sorry this is a tough time.”
(reassure) “I love you and we’re going to get through this together.”
(distract) “You know what? Don has a new job. He’s really excited about it.”

Do repeat exactly.

PWD: “I’m going to the store for a newspaper.”

Don’t: (repeat differently) “Please put your shoes on.” “You’ll need to put your shoes on.”

DO: (repeat exactly) “Please put your shoes on.” “Please put your shoes on.”

Don’t remind them they forget.

PWD: “Joe hasn’t called for a long time. I hope he’s okay.”

Don’t: (remind) “Joe called yesterday and you talked to him for 15 minutes.”

DO: (reassure) “You really like talking to Joe, don’t you?”
(distract) “Let’s call him when we get back from our walk”

Do eliminate ‘but’, substitute ‘nevertheless’.

PWD: “I’m not eating this. I hate chicken.”

Don’t: (say ‘but’) “I know chicken’s not your favorite food, but it’s what we’re having for dinner.”

DO: (say ‘nevertheless’) “I know chicken’s not your favorite food, (smile) *nevertheless* I’d appreciate it if you’d eat a little bit.”

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Home Safety Tips

☐ **Register with SAFE RETURN**. Be sure to include a current photo with your application.
☐ Make neighbors aware of your loved one's diagnosis so that if they notice your loved one wandering they will quickly alert you.
☐ Be attentive around your loved one; always be looking for new potential hazards in the environment.
☐ Find a good "handyman" that is dependable and can help you at short notice.
☐ Lock up or dispose of toxic materials such as cleaning fluids, insecticides, and medicines so that they are not accidentally ingested by your loved one who has memory problems.
☐ Learn to disable the car. A person with memory loss should never drive; they can easily get lost and cannot react quickly enough or appropriately to road hazards. Do not risk the life of your loved one or other innocent people on the road.
☐ Place locks on the top of doors, out of sight line. Installing doorbells will alert the caregiver if the door opens or closes.
☐ Cover or remove mirrors-especially in the bathroom. A person with memory loss may interpret their reflection as a stranger in the home and could lead to an accident.
☐ Remove unnecessary rugs to prevent falls or secure rugs (and other easily movable furniture) with a non-slip type backing.
☐ Remove unnecessary furniture to keep walkways clear but try not to rearrange furniture unless absolutely necessary.
☐ Keep decoration simple with plain walls and carpets and eliminate clutter.
☐ Remove poisonous plants (like oleander) so they are not mistakenly eaten.
☐ Place a lock on the thermostat and water heater so that a person with dementia cannot adjust them. Be aware that to prevent burns water should be no hotter than 120° F.
☐ Install a fire extinguisher in the kitchen.
☐ Remove knobs from the stove so that the person with memory loss cannot switch it on. Install child safety latches on the inside of cabinets where cleaning products are kept.
☐ Place non-slip mats in showers and tubs.
☐ Install grab-bars by the toilet, shower, and bath. Towel rails are NOT a substitute.
☐ Learn the Heimlich maneuver.
☐ Install night-lights, especially between bedrooms and bathrooms.
☐ Install pool safety devices including gate locks.
☐ Post important numbers by the telephone: police, fire, family, and friends.
☐ Keep a recent photo of your loved one available. Have a plan for your loved one in case you, the caregiver, are unable to provide care.

Call the Alzheimer's Association Desert Southwest Chapter for literature and tips to create a safe home for persons with memory loss, at 800.272.3900 or online at www.alz.org/dsw.

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January 2013

Alzheimer's Caregiving Tips

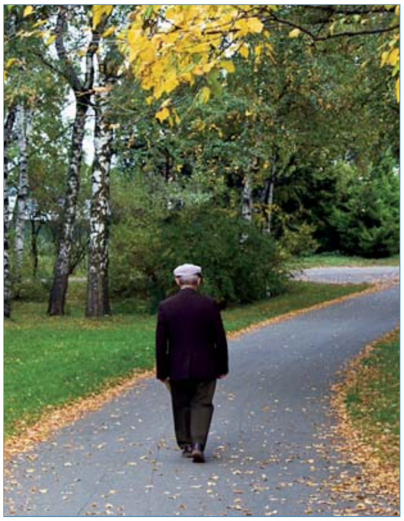
Wandering

Many people with Alzheimer's disease wander away from their home or caregiver. As the caregiver, you need to know how to limit wandering and prevent the person from becoming lost. This will help keep the person safe and give you greater peace of mind.

First Steps

Try to follow these steps *before* the person with Alzheimer's disease wanders:

- Make sure the person carries some kind of ID or wears a medical bracelet. If the person gets lost and can't communicate clearly, an ID will let others know about his or her illness. It also shows where the person lives.
- Consider enrolling the person in the MedicAlert® + Alzheimer's Association Safe Return® Program (see *www.alz.org* or call 1-888-572-8566 to find the program in your area).
- Let neighbors and the local police know that the person with Alzheimer's tends to wander. Ask them to alert you immediately if the person is seen alone and on the move.
- Place labels in garments to aid in identification.
- Keep an article of the person's worn, unwashed clothing in a plastic bag to aid in finding him or her with the use of dogs.
- Keep a recent photograph or video recording of the person to help police if he or she becomes lost.



Tips to Prevent Wandering

Here are some tips to help prevent the person with Alzheimer's from wandering away from home:

- Keep doors locked. Consider a keyed deadbolt, or add another lock placed up high or down low on the door. If the person can open a lock, you may need to get a new latch or lock.*

CarePRO:
Care Partners Reaching Out

Developing the Skills Needed to Care for Someone with Dementia or Memory Loss

- Are you a family caregiver residing in Arizona that helps care for someone with dementia or memory loss?
- Do you provide an average of 4 hours of care or supervision per day for that individual?
- Do you find caring for your loved one increasingly demanding of your time and energy?

If so, CarePRO may be able to help you. Through our free workshops, you will learn:

- About dementia and its impact
- How to manage your frustration, irritation, and stress
- How to communicate with your loved one
- How to take better care of your own health

For more information, please call:
Alzheimer's Association
520-322-6601
1-800-272-3900 (outside of Pima County)
Please see reverse for details

Section 7

Supportive Housing

Making the Decision
When is the right time for facility care?

It is difficult to know when to begin looking for facility care for a loved one. However, if you are the primary care provider for someone with Alzheimer's disease (AD) or a related dementia, you may begin asking this question as the disease progresses. The most important thing to remember is that there is no "right" time for everyone. Each individual and family is different, and there are several factors to consider. To discuss these factors a family meeting is recommended including family, close friends & neighbors, and when appropriate, the person with Alzheimer's disease (AD) or related dementia. Use the checklist below to help you assess your caregiving situation.

Safety

- ☐ Does your loved one forget or refuse to use safety equipment such as wheelchairs, walkers, or grab bars?
- ☐ Is the home environment becoming more difficult for the person with AD or related dementia? (e.g., stairs, in accessible doors, dark hallways)
- ☐ Has your loved one had accidents with the stove, appliances, or other household items?
- ☐ Has the person with AD or a related dementia had trouble getting around the house without falling or needing assistance with walking?
- ☐ If your loved one smokes, has he had smoking accidents? (e.g. forgetting to extinguish cigarettes and burning holes in clothing)

Personal Hygiene

- ☐ Is it difficult for your loved one to get to the bathroom when needed?
- ☐ Is the person with AD or a related dementia unwilling or unable to bathe?
- ☐ Is the person with AD or a related dementia unwilling or unable to change clothing when needed?
- ☐ Is your loved one unable or unwilling to help with personal care task?
- ☐ Have care needs for your loved one become too difficult or too demanding for you?

Behavioral Concerns

- ☐ Has your loved one ever wandered away from home or been lost?
- ☐ Is your loved one combative, suspicious, angry, or refusing care?
- ☐ Has the person with AD physically harmed himself or you at any time in the past?

Nutrition

- ☐ Does this person with AD or a related dementia have trouble preparing meals or eating independently?
- ☐ Do you have difficulty encouraging your loved one to eat appropriate, nutritious foods?
- ☐ Is your loved one having health problems associated with poor nutrition? (e.g. vitamin deficiency, dehydration, weight loss, other illness)
- ☐ Have eating and/or swallowing become difficult for the person with AD or a related dementia?

Time and Energy

- ☐ Does your loved one need help with most Activities of Daily Living (ADLs)? (e.g. eating, bathing, dressing, personal hygiene)
- ☐ Do housekeeping duties need to be done so frequently that care becomes an excessive demand?
- ☐ Have you frequently lost sleep at night due to worrying about caregiving?

Financial Concerns

- ☐ Do you or would you have difficulty affording in-home help 24 hours a day?
- ☐ Have the financial strains of caregiving been difficult on your personal budget? (e.g. durable medical equipment cost, incontinence, food and prescription drug purchases)
- ☐ Do you miss work frequently due to your caregiver responsibilities?

Caregiver Issues

- ☐ At the end of the day, have you felt like you couldn't make it through another day? Is this a recurring thought?
- ☐ Is you health at risk or beginning to suffer because of your caregiving responsibilities?
- ☐ Have you lost your privacy or the ability to organize and run your household?
- ☐ Is there frequent conflict between household members related to caregiving issues?
- ☐ When you get a break from caregiving, do you still feel overwhelmed and exhausted?

In-home Care

- ☐ Have you tried and been unsuccessful with in-home services such as housekeeping, delivered meals, personal and companion care?
- ☐ Have you had difficulty getting your loved one to attend adult day programs?
- ☐ Has overnight respite care been used?
- ☐ Have you had difficulty enlisting the assistance of family and friends to give yourself a break?

If you answered "yes" to many of these questions, you may need to begin thinking about alternative care options. These are just some of the factors to consider when making this difficult decision. Individual personalities, family history, and outside support should always be part of your decision.

Adapted from the Alzheimer's Association, Oregon Trail Chapter

Alzheimer's Association Desert Southwest ChapterSouthern Arizona Region
1159 N. Craycroft Road
Tucson, Arizona 85712
520.322.6601
800.272.3900

Remember to…

- Plan ahead to prevent making decisions during a crisis.
- It is all right to ask for help – you need emotional and physical support.
- You are doing the best you can!

Supportive Housing for Older Adults

If you are considering supportive housing, there are a few different types of environments to choose from. The most appropriate type of housing will depend upon your needs or anticipated needs.

Retirement Apartments (Independent Living)
Meals, transportation, activities, security, housekeeping, emergency response system are provided to residents in individual apartments.
Cost: $980–$5000/mo. Meal plans vary. Additional services may be available for a fee.

Assisted Living Centers
Apartment setting with meals, transportation, activities, housekeeping, 24-hour supervision, administration of medications, assistance with personal care. More than 10 residents. Specialized dementia care may be available.
Cost: Prices vary depending upon care needs, room size and amenities. Average base monthly cost (exclusive of care needs) in Tucson in 2012 was $3,443/month or $41,316/year. Subsidies available if eligible: Arizona Long Term Care System in contracted centers, Veterans Administration. There are two sliding fee scale facilities in Tucson: St. Luke's Home (520) 628-1512 and Marshall Home For Men (520) 624-5193. Regulated by the Arizona Department of Health Services.

Assisted Living Homes (Adult Care Homes)
Private home caring for up to 10 older adults. Services include housekeeping, meals, 24-hour supervision, and assistance with personal care, medication administration and activities. Specialized dementia care is available in some homes.
Cost: Usually $2,000–$5,000/month and up depending upon care, room size and amenities. Subsidies available if eligible: Arizona Long Term Care System in contracted homes, Veterans Administration. Regulated by the Arizona Department of Health Services. Referral agencies can assist families in finding a home.

Skilled Nursing Facilities
Residential health care facility offering ongoing nursing care. Three levels of care may be offered: intermediate care, skilled care, dementia/secure.
Cost: Depends upon care needs, room size and amenities. Average cost in Tucson in 2012 was $218/day for a private room ($79,570/year); $186/day for a shared room ($67,890/year). Subsidies available: Arizona Long Term Care System, Veterans Administration. Medicare generally pays for rehabilitation only. Regulated by the Arizona Department of Health Services.

Continuing Care Retirement Community (CCRC)
CCRCs offer a full continuum of care, ranging from independent retirement apartments or villas, to assistance with personal care in assisted living apartments, to long-term care in a skilled nursing facility. Designed to allow residents to receive all their care needs on the same campus. Types of contracts available vary.

PCOA
PIMA COUNCIL ON AGING
Advocacy, Action, Assistance

Selecting Residential Care for Older Adults

- Determine that the facility provides the level of care needed by you or your loved one now and in the near future. Be realistic about care needs.
- Make a scheduled visit first and unannounced follow up visits.
- Ask to see a copy of the most recent survey by the Department of Health Services. Have there been complaints filed/deficiencies noted against the institution? If so, what were they?
- Does the facility have a contract to provide care to residents in the Arizona Long Term Care System (ALTCS)?
- What is the monthly base fee and what services does it cover? What additional services are there and do they cost extra? Is there an itemized list of services? Is there a move-in fee?
- Under what conditions might fees increase? What are the conditions for terminating a contract? How much notice will be given? What is the refund policy?
- What if the older adult must be hospitalized or needs another level of care? What is the procedure if care needs increase above that which the facility can provide? How much notice will be provided?
- Do research on the ownership of the facility. Interview the executive director/owner/manager. How long has he or she been at that facility? What is his or her philosophy of care?
- Can they accommodate couples and are the fees specific to the individual care needs?
- Do physicians or registered nurses regularly visit the facility?
- Review the documentation of medication administration. What techniques are used if someone with dementia refuses his or her meds?
- What is the ratio of staff to residents, including on weekends and at night? Is there awake staff available 24 hours per day? How often are residents checked at night?
- How are caregivers screened? What background checks are done? What initial and continuing education is required? How are their skills evaluated and their credentials checked? How long has staff been at the facility?
- Have caregivers received specific training in dementia care? How do staff handle difficult behaviors?
- Are caregivers available with the physical strength and training necessary to perform safe transfers or whatever task is required?
- Are caregivers available with the cultural sensitivity and language skills you or your loved one need?
- Is this facility able to meet your or your loved one’s specific requirements (e.g., non-smoking, fragrance free, etc.)?

- Does the agency have nondiscrimination policies and provide staff training on cultural competency issues including lesbian, gay, bisexual, and transgender (LGBT) concerns?
- How are complaints made and how are they handled?
- Is the environment attractive, both indoors and outdoors?
- Are sanitary conditions maintained throughout the facility?
- Are residents addressed by appropriate names?
- Are residents appropriately dressed and groomed for time of day?
- Do caregivers knock before entering a resident's room?
- Are residents cheerful and able to talk freely with you?
- Ask for a copy of the monthly activity calendar to see if the activities would interest you or your loved one.
- Is there meaningful stimulating activity available at the needed frequency and level?
- How far do residents have to walk to activities and to their dining room?
- Will the distance be a barrier to participation in activities or meals for you or your loved one?
- Can residents decorate their own rooms? How are roommates selected?
- Ask to see a menu. Can the facility accommodate special dietary needs?
- Do residents participate in menu planning if desired? Are snacks available between meals?
- Is there an emergency call system? Is it conveniently located? Who responds to the call?
- Is there private phone service in each room?
- Are visitors welcome at any time? Could pets live in or make visits?
- Are visitors monitored or screened in any way?

The following websites may be useful: www.medicare.gov for nursing home information, and www.azdhs.gov/als for information on assisted living homes and centers. For information about survey results or complaints you may contact the Tucson branch of the Department of Health Services Healthcare Licensure at (520) 628-6965.

Resident's Rights In Care Facilities

Residents of long-term care facilities have the right to:

- Be treated with respect and dignity
- Be free from chemical and physical restraints
- Manage their own finances
- Voice grievances without fear of retaliation
- Associate and communicate privately with any person of their choice
- Send and receive personal mail
- Have personal and medical records kept confidential
- Apply for State and Federal assistance without discrimination
- Be fully informed prior to admission of their rights, services available, and all charges
- Be given advance notice of transfer or discharge

For more information, go to the website www.azdes.gov/daas/ltco/

Source: Arizona Long Term Care Ombudsman Program
Division of Aging and Adult Services and the Area Agencies on Aging

Advocacy for Individuals in Residential Settings

When a loved one moves to a long term care facility, concerns may arise about the care he or she is receiving. There are several agencies that can deal with complaints or concerns as well as those that regularly monitor and report on these facilities:

Pima Council on Aging (PCOA) Long Term Care Ombudsman Program
Website: www.pcoa.org
Help Line: (520) 790-7262
E-mail: ltco@pcoa.org

The Long Term Care Ombudsman Program at PCOA consists of trained volunteers and staff who regularly visit assisted living and nursing home residents in Pima County to monitor the facilities and advocate for residents' rights. Working with residents and their families along with the facilities, the ombudsmen investigate and resolve problems, provide information, referral and consultation and work with licensing, certification, and other enforcement agencies to improve the quality of care in long term care facilities. The ombudsmen also identify problem areas in facilities and advocate for change.
The ombudsmen can help with concerns and problems about:

- The quality of long term care provided
- Residents' rights
- Physical abuse and neglect
- Dietary needs
- Privacy and confidentiality
- Financial issues (e.g. billing, government benefits, financial exploitation)
- Physical or chemical restraints
- Facility transfer or discharge

Adult Protective Services (APS)
Online reporting: www.azdes.gov/reportadultabuse
Telephone reporting: (877) 767-2385

- Monday-Friday 7 a.m. - 7 p.m. / Sat-Sun 10 a.m. - 6 p.m.

APS is a state-wide program that receives and investigates reports of possible neglect, abuse and exploitation of vulnerable adults. APS workers conduct investigations in facilities as well as in private homes and apartments. A vulnerable adult is defined as an individual who is 18 years of age or older who is unable to protect him/herself from abuse, neglect or exploitation by others because of a physical or mental impairment. APS works in partnership with law enforcement, the courts and community-based service providers to facilitate services and supports that help protect vulnerable adults from abuse, neglect and exploitation, and help them live as independently as possible.

Arizona Department of Health Services (ADHS)
Website: www.azdhs.gov

General information: (602) 542-1025
Licensing Services: (602) 364-2536

The ADHS Division of Licensing Services licenses and monitors health and child care facilities and providers throughout Arizona. Licensing inspections, on-site surveys (usually done annually), and complaint investigations are conducted to promote quality care and safety and ensure that performance standards are met for facility operation and maintenance. The website includes AZ Care Check, where you can find information about deficiencies found in facilities. You can also submit complaints about nursing homes or assisted living facilities online. The Division of Licensing Services includes two separate offices, Long Term Care that inspects nursing homes and Assisted Living Facilities, Assisted Living Homes and Centers, and Adult Foster Care. You can also find the most recent federal inspection survey results at: www.medicare.gov/nursinghomecompare.

Factors to consider in evaluating a facility:

- Residents' lack of proper hygiene
- Bedsores (pressure sores)
- Inadequate number of staff
- Unsafe environment (e.g. tears in carpet, broken furniture)
- Urine or fecal odors
- Restrained residents
- Inadequate records
- Poor supervision of staff
- Unexplained injuries
- Alleged abuse
- Not enough food
- Inadequate clothing

Arizona Center for Disability Law (ACDL)
Website: www.acdl.com
Intake: 602-274-6287 (Voice/TTY) or (800) 927-2260 (Voice/TTY)

The ACDL is a federally-designated Protection and Advocacy System for the State of Arizona. Protection and Advocacy Systems (P&As) throughout the United States assure that the human and civil rights of persons with disabilities are protected. In creating P&As, Congress gave them unique authorities and responsibilities, including the power to investigate reports of abuse and neglect and violations of the rights of persons with disabilities. P&A's are also authorized to pursue appropriate legal and administrative remedies on behalf of persons with disabilities to insure the enforcement of their constitutional and statutory rights.

Source: Pima Council on Aging

Glossary:
Frequently Used Terms in Long-Term Care

Adult Day Health Care Center
(ADHC) A structured program that is usually offered on weekdays and may offer activities, meals, and health and rehabilitative services for the elderly in a supervised setting. Transportation is sometimes included in the fee. ALTCS covers this benefit.

Activities of Daily Living (ADLs)

- Examples of ADLs are:
- Bathing
- Dressing
- Grooming
- Eating
- Bed mobility
- Transferring
- Toileting
- Walking

Advance Directives
These are documents that allow individuals to designate decisions they want to have made and who will be authorized to make those decisions for medical and related care. They take effect when patient becomes mentally or physically unable to make or communicate wishes. Living Wills, Durable Power of Attorney for Healthcare and Durable Mental Healthcare Power of Attorney are examples of advance directives.

Alzheimer's Disease
Alzheimer's disease ("AD") is the most common of the dementia disorders. It is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. Symptoms include:

- Gradual memory loss
- Decline in ability to perform routine tasks
- Disorientation in time and space
- Impairment of judgment
- Personality change
- Difficulty in learning
- Loss of language and communication skills

As with all dementia, the rate of progression in Alzheimer's patients varies from case to case. Refer to your local chapter of the Alzheimer's Association or www.alz.org for more assistance.

Application Date
The date the ALTCS application is received by the eligibility agency.

Assisted Living (Non-Medical Senior Housing)
Assisted living is a general term for living arrangements in which some services are available to residents (meals, laundry, and medication reminders) but residents still live independently within the assisted living complex. In most cases, assisted living residents pay a regular monthly rent, and then pay additional fees for the services they require. ALTCS covers service in many situations. The facility should be asked if they have a contract with the ALTCS program.

Assisted Living Center – (ten or fewer residents)
These are group living arrangements (sometimes called group or domiciliary homes) that are designed to meet the needs of people who cannot live independently, but do not require nursing home services.

Assisted Living Homes - (four or fewer residents)
Private homes that take in four or fewer residents and care for them 24 hours a day. More of a family environment. ALTCS covers this benefit.

Attendant Care
A service benefit of the ALTCS program whereby a family member, friend, neighbor, or loved one can be paid to be the member's caregiver. The only person not eligible to be paid is the parent of a member who is under 18.

Case Manager (Care Manager)
A social worker or health care professional, who evaluates, plans, locates, coordinates and monitors services with an older person and the family. Once on the ALTCS program, a case manager is assigned to the member to coordinate service. These professionals have access to your loved one's needs and home situation and they coordinate and monitor the necessary care and services. They work closely with you and other family members, making it possible even for those who live far away to stay involved. ALTCS covers this service.

Conservator
Person appointed by the court in a legal proceeding to act as the legal and financial representative of a person who is mentally or physically incapable of managing his or her own financial affairs.

Co-Payment
This is the portion of a medical expense that is the member's financial responsibility. HMOs generally have fixed low co-payments, usually around $5 - $10.

Continuing Care Retirement Communities (CCRC's)
CCRC's are housing communities that provide different levels of care based on the needs of their residents from independent living apartments to skilled nursing in an affiliated nursing home. Residents move from one setting to another based on their needs, but continue to remain a part of their CCRC's community. Many CCRC's require a large payment prior to admission and charge monthly fees beyond that. For this reason, many CCRC's are too expensive for older people with modest incomes.

Deductible
A common cost-sharing arrangement of traditional indemnity insurers under which a policyholder must pay a set amount toward covered services before the insurer is required to pay claims.

Dementia
Dementia is characterized by the loss of intellectual functions such as thinking, remembering and reasoning to the extent that a person's daily functioning is affected. It is not a disease in itself, but rather a group of symptoms which may accompany certain diseases or physical conditions. The cause and rate of progression of dementia vary. Some of the well-known diseases that produce dementia include:

Alzheimer's Disease
Multi-infarct Dementia
Huntington's Disease
Pick's Disease
Creutzfeldt-Jakob Disease
Parkinson's Disease
Depression

Depression
Depression is a psychiatric disorder marked by sadness, inactivity, feelings of hopelessness, and sometimes suicidal tendencies. Many severely depressed individuals will have some mental deficits including poor concentration and attention. When dementia and depression are present together, intellectual deterioration may be exaggerated. Depression, whether present alone or in combination with dementia, can be reversed with proper treatment.

Durable Power of Attorney
A power of attorney is a document where one person (the principal) appoints another person (the agent) to act on behalf of the principal. A Durable Power of Attorney survives the incapacity of the principal.

Enrollment Date
The date AHCCCS enrolls the person in a health plan (Program Contractor).

Estate Planning
Steps you can take while living to determine what happens to your property when you die.

Gatekeeper
A term sometimes used to refer to HMO primary care physicians or nurse practitioners and Case Managers because of their responsibility for referring members to specialists or other services.

Gifting
Giving funds to charity, family or other entity.

Guardian
Person appointed by court to make personal, placement and medical decisions for someone who is incapacitated.

HMO (Health Maintenance Organization)
A health plan that both pays for and provides, or arranges to provide, access to comprehensive medical services. HMOs are reimbursed for services on a fixed monthly basis.

Incapacity
The inability to make or communicate personal decisions. Incapacity can be mental or physical, temporary or permanent.

Long-Term Care Facilities/Skilled Nursing Facilities/Nursing Home
A nursing home is a residence that provides room, meals, recreational activities, help with daily living and protective supervision to residents. Generally, nursing home residents have physical or mental impairments which keep them from living independently. Nursing homes are certified to provide different levels of care, from custodial to skilled nursing (services that can only be administered by a trained professional). Cost can be covered by the ALTCS program.

Health Care Power of Attorney
Allows a designated representative to make health care decisions for a person who is incapacitated.

Home and Community Care
Most people want to remain at home as long as possible. A person who is ill or disabled and needs help may be able to get a variety of home services that might prevent one from having to move into a nursing home. Home and community based services (HCBS) include:
Personal care
Respite care
Medical transportation
Nursing care
Home health aide
Home modification
Attendant care
Adult day care
Durable medical equipment

Home Health Agency
An organization that provides home care services, including skilled nursing care, physical therapy, occupational therapy, speech therapy and care by home health aides.

Home Health Aide
A home health aide does not have a nursing license. The aide provides services that support any services that the nurse provides. ALTCS covers this service.

Irrevocable
Unchangeable or irreversible.

Living Will
A document that makes known a person's wishes regarding medical treatments, usually for those at the end of life.

Long-Term Care Insurance
Private insurance designed to cover long-term care costs. These insurance plans vary greatly, and it is wise to do some research before purchasing any long-term care policy. Generally, only relatively healthy people may purchase long-term care insurance.

Managed Care
A method of delivering and paying for health care through a system of networks of providers. Managed care seeks to ensure the quality and contain the cost of comprehensive medical care. Managed care plans include HMOs, preferred provider organizations, point of service plans and similar coordinated care networks.

Medicaid/Medical Assistance

A joint federal and state program that helps with medical costs for some people with low incomes. Programs vary from state to state, but most health care costs are covered if one qualifies for both Medicare and Medicaid. ALTCS is Arizona's version of Medicaid for chronically ill elderly and the disabled.

Medicare

Federal program providing health care coverage/insurance for people over 65 years of age, certain younger people with disabilities, and people with End-Stage Renal Disease (ESRD) (permanent kidney failure that must be treated with dialysis or a transplant). Part A covers inpatient care, skilled nursing facility, hospice and short-term health care. Part B covers doctors' services, outpatient hospital care and durable medical equipment. It does not provide for long-term care of the elderly except under limited conditions.

Medical Social Services

Help with social and emotional concerns one may have related to one's illness. This might include counseling or help in finding community resources.

Medicare Supplemental Insurance

This is private insurance (often called Medigap) that pays Medicare's deductibles and coinsurances, and which may cover services not covered by Medicare. Most Medigap plans will help pay for skilled nursing care, but only when that care is covered by Medicare.

Medigap Policies

A Medigap policy is the most common way that a health insurance policy helps one pay for some nursing home costs. A Medigap policy pays for the 'gaps,' or co-insurance, left by Medicare such as the co-pay owed for days 21 through 100 of a Medicare Benefit period. Premium payments for new Medigap policies usually range from approximately $50.00 to $150.00 per month.

Out-of-Pocket Costs

Costs for medical services not covered by an insurer or an HMO. Unlike persons with conventional insurance, HMO members incur minimal out-of-pocket costs.

Parkinson's Disease

Parkinson's disease ("PD") is a progressive disorder of the central nervous system which affects more than one million Americans. Individuals with PD lack a substance called dopamine, which is important in the central nervous system's control of muscle activity. PD is often characterized by:

- Tremors
- Stiffness in limbs and joints
- Speech impediments
- Difficulty in initiating physical movement

Late in the course of the disease, some individuals develop dementia and eventually Alzheimer's disease. Medications such as levodopa, which prevents degeneration of dopamine, are used to improve diminished motor symptoms in PD patients but do not correct the mental changes that it causes. Contact www.bni.org or (602) 406-4931.

Revocable
Capable of being revoked or changed

Share of Cost
The amount the ALTCS member must pay out of their income towards the cost of their long term care services. In assisted living, this amount is called "room and board."

SNF
SNF stands for "skilled nursing facility."

Trust
A trust may be used for management of assets during a person's lifetime.

Source: JacksonWhite Attorneys At Law

www.arizonaseniorlaw.com
(480) 464-1111 / (800)243-1160

Section 8

Medicare, Long-Term Care, Social Security and Veterans

CMS CENTERS FOR MEDICARE & MEDICAID SERVICES

PCOA
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Advocacy, Action, Assistance

ship state health insurance assistance programs
NATIONAL NETWORK

What is Medicare?

Medicare is health insurance for:

- People 65 or older
- People under 65 with certain disabilities
- People of any age with End-Stage Renal Disease (ESRD) (permanent kidney failure requiring dialysis or a kidney transplant)

What are the different parts of Medicare?

Medicare Part A (Hospital Insurance) helps cover:

- Inpatient care in hospitals
- Skilled nursing facility care
- Hospice care
- Home health care

You usually don't pay a monthly premium for Part A coverage if you or your spouse paid Medicare taxes while working. This is sometimes called premium-free Part A. If you aren't eligible for premium-free Part A, you may be able to buy Part A, and pay a premium.

Medicare Part B (Medical Insurance) helps cover:

- Services from doctors and other health care providers
- Outpatient care
- Home health care
- Durable medical equipment
- Some preventive services

Most people pay the standard monthly Part B premium.

Note: You may want to get coverage that fills gaps in Original Medicare coverage. You can choose to buy a Medicare Supplement Insurance (Medigap) policy from a private company.

Medicare Part C (Medicare Advantage):

- Run by Medicare-approved private insurance companies
- Includes all benefits and services covered under Part A and Part B
- Usually includes Medicare prescription drug coverage (Part D) as part of the plan
- Usually includes extra benefits and services, in some cases for an extra cost

Medicare Part D (Medicare prescription drug coverage):

- Run by Medicare-approved private insurance companies
- Helps cover the cost of prescription drugs
- May help lower your prescription drug costs and help protect against higher costs in the future

Note: If you have limited income and resources, you may qualify for help to pay for some health care and prescription drug costs. For more information, contact your State Medical Assistance (Medicaid) office, visit socialsecurity.gov, or call Social Security at 1-800-772-1213. TTY users should call 1-800-325-0778. If you have questions about Medicare, visit Medicare.gov, or call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

Contact Pima Council on Aging for a no-cost health insurance benefits counseling service for Medicare beneficiaries, caregivers and their families in Pima County that provides easy-to-understand information about Medicare coverage and financial assistance programs. Medicare counselors are trained in Medicare eligibility, benefits and options, health insurance counseling and related insurance products. The program is not connected to any insurance company so you can be sure you are getting accurate and objective information to help you make decisions about Medicare coverage. Call the Medicare line at (520) 546-2011 or email ship@pcoa.org.

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Frequently Used Medicare Acronyms

ABN - Beneficiary Notice - a written notice given to a Medicare beneficiary by a physician, provider or supplier before an item or service is rendered, when the item or service is expected to be denied by Medicare.

AEP - Annual Enrollment Period - the time frame when Medicare beneficiaries can change their health care coverage. The AEP is from October 15th through December 7th each year.

AHCCCS - Arizona Health Care Cost Containment System - Arizona's Medicaid Agency that offers health care programs to serve Arizona residents who meet income and other requirements.

CMS - Centers for Medicare and Medicaid Services - the federal agency that oversees the Medicare and Medicaid programs.

DME - Durable Medicare Equipment - reusable medical equipment such as walkers, wheelchairs and hospital beds. Coverage is provided by Part B, when medically necessary.

HMO - Health Maintenance Organization - a type of Medicare Advantage Plan that usually requires the use of network providers.

IEP - Initial Enrollment Period - the 7-month period when people can apply for Medicare…includes 3 months before age 65, month of 65th birthday and 3 months after 65th birthday. If a person has Medicare due to disability, the same time frame applies, beginning with 3 months before their Medicare begins.

LIS - Low Income Subsidy - extra help with prescription drug costs, for people with limited income and resources.

MA-PDP - Medicare Advantage Prescription Drug Plan - a Medicare Advantage Plan (like a HMO or PPO) that includes prescription drug coverage.

MSN - Medicare Summary Notice - an explanation of benefits provided by Medicare, after a claim has been processed.

MSP - Medicare Savings Programs - programs that help low-income individuals with Medicare costs (premiums, co-pays and medications). The 3 programs are QMB, SLMB and QI.

PFFS - Private Fee-For-Service - a type of Medicare Advantage Plan that allows a person to see any provider that agrees to treat them and accept the plan's payment. Some areas require the use of network providers.

PPO - Preferred Provider Organization - a type of Medicare Advantage Plan that has a provider network. This type of plan allows you to use out of network providers, but at higher out of pocket costs.

QI - Qualified Individual - an AHCCCS program that pays the Medicare Part B premium and lowers Part D costs for those with low incomes.

QIO - Quality Improvement Organization - an organization that is made up primarily of medical professionals to oversee the quality of care for Medicare beneficiaries. Arizona's QIO is Health Services Advisory Group (HSAG).

QMB - Qualified Medicare Beneficiary - an AHCCCS program that pays the Part B premium, deductibles and coinsurance, and lowers Part D copays for low-income Medicare beneficiaries.

SEP - Special Enrollment Period - time frames that are outside the initial enrollment periods, when people are allowed enroll in certain coverages.

SLMB - Specified Low Income Medicare Beneficiary - an AHCCCS program that pays the Part B premium and lowers Part D costs for low income individuals.

SMP - Senior Medicare Patrol - a federal program that educates seniors as to how to identify and report Medicare fraud, errors and abuse.

SNF - Skilled Nursing Facility - a facility that provides skilled nursing care and rehab services to Medicare beneficiaries after a qualifying hospital stay.

SSA - Social Security Administration - the federal agency that processes applications for Social Security, SSI and Medicare.

SSDI - Social Security Disability Insurance - a federal insurance program managed by the Social Security Administration. It is designed to provide income supplements to people who are unable to work due to disability.

SSI - Supplemental Security Income - a federal income supplement funded by general tax revenues (not Social Security taxes).

State Health Insurance Program

The Arizona State Health Insurance Assistance Program (SHIP) is a no-cost one-on-one personal health benefits counseling program for Medicare beneficiaries and their families or caregivers. Medicare counselors can explain your options, assist you in comparing plans and help you understand how Medicare works with other insurance plans. Trained staff and volunteers provide unbiased information and can help with:

- Medicare eligibility and benefits
- Original Medicare
- Medigap insurance
- Medicare Advantage Plans
- Understanding and enrolling in Medicare Part D
- Long Term Care Insurance
- Medicare and AHCCCS

Welcome to Medicare workshops are offered once a month.

The **SHIP** is an independent program funded by the Administration for Community Living and the Centers for Medicare and Medicaid Services and is not affiliated with the insurance industry.

The **Senior Medicare Patrol (SMP)** is a **SHIP** program that empowers seniors to prevent healthcare fraud. Healthcare fraud, waste, and abuse cost American taxpayers nearly $60 billion each year. This program recruits and trains retired professionals and other older adults who provide presentations about how to:

- Identify potential scams and other fraudulent activity
- Protect personal information including Medicare and Social Security numbers
- Detect errors on Medicare Summary Notices (MSN's) or Explanations of Benefits (EOB's)
- Report suspected fraud or abuse to the proper authorities

For assistance with Medicare, to attend a workshop, to request a presentation, or to learn more about SMP, call the Medicare Line at Pima Council on Aging at **(520) 546-2011.**

Long-Term Care Insurance: What You Should Know

What is Long-term Care?

Long-term care refers to a wide range of medical, personal and social services. You may need this type of care if you have a prolonged illness or disability. This care may include help with daily activities, as well as home health care, adult daycare, nursing home care or care in a group living facility. Long-term care insurance is one way to pay for long-term care. It is designed to cover all or some of the services provided by long-term care.

When will benefits be available?

Long-term care policies have an elimination period, which is the number of days you must need nursing home care or home health care before your policy pays benefits. A shorter elimination period will mean you pay a higher premium. Elimination periods may range from 0 to 180 days. In addition, a long-term care policy does not guarantee coverage unless you satisfy certain requirements. For example, most policies require that you be unable to perform a given number of daily living activities, such as dressing, bathing and eating without assistance. Also, most policies have a benefit trigger for cognitive impairment. For example: as a policyholder you can only qualify for these benefits if you are unable to pass a test assessing your mental functioning.

How much in benefits will the policy pay?

The benefit amount usually is a daily benefit ranging from $50 to $250 per day. You may choose a benefit period that is a specific number of days, months or years. A maximum benefit period may range from one year to the remainder of your lifetime. It is important to ask the person selling the policy if the benefit amounts will increase with inflation and if that coverage increases your premium.

Are there exclusions?

Every policy has an exclusion section. Some states do not allow certain exclusions. Many long-term care policies exclude coverage for the following:

- Mental and nervous disorders or diseases (except organic brain disorders)
- Alcoholism and drug addiction
- Illnesses caused by an act of war
- Treatment already paid for by the government
- Attempted suicide or self-inflicted injury

Considerations before buying long-term care insurance

Whether you should buy long-term care insurance depends on your age and life expectancy, gender, family situation, health status, income and assets.

- Age and Life Expectancy: The longer you live, the more likely it is that you will need long-term care. The younger you are when you buy the insurance, the lower your premiums will be.
- Gender: Women are more likely to need long-term care because they have longer life expectancies and often outlive their husbands.

- Family Situation: If you have a spouse or adult children, you may be more likely to receive care at home from family members. If family care is not available and you cannot care for yourself, paid care outside the home may be the only alternative. Different policies may cover different types of long-term care. It is important to buy a policy that will cover the type of care you expect to need and will be available in your area.
- Health Status: If chronic or debilitating health conditions run in your family, you could be at greater risk than another person of the same age and gender.
- Income and Assets: You may choose to buy a long-term care policy to protect assets you have accumulated. On the other hand, a long-term care policy is not a good choice if you have few assets or a limited income. Some experts recommend you spend no more than five percent of your income on a long-term care policy.

Do you qualify for Medicaid?

As an older adult, you may qualify for Medicaid, which pays almost half of the nation's long–term care bills. To qualify for Medicaid, your monthly income must be less than the federal poverty level, and your assets cannot exceed certain limits. Medicaid will cover you only in Medicaid-approved nursing homes that offer the level of care you need. Under certain circumstances, Medicaid will pay for home health care.

Some states have long-term care insurance programs designed to help people with the financial impact of spending down to meet Medicaid eligibility standards. Under these "partnership" programs, when you buy a federally qualified partnership policy, you will receive partial protection against the normal Medicaid requirement to spend down your assets to become eligible. Check with your state insurance department or a counseling program to see if these policies are available in your state.

Key points to remember

- Long-term care insurance policies cover a wide range of medical, personal and social services.
- Understand what must happen for a policy to begin paying benefits.
- Understand the elimination period.
- Understand the daily benefits provided.
- Understand your coverage and exclusions.
- Match your need for long-term care with your need to protect assets and your ability to pay premiums.
- Understand how much your premium will be and how often it must be paid.
- Your premium may increase after your purchase.

The website for the National Clearinghouse for Long-Term Care Information features a number of resources to help individuals start the planning process, including interactive tools such as a savings calculator, contact information for a range of programs and services, and real-life examples of how individuals have planned successfully for long-term care.

The Clearinghouse was authorized by the Deficit Reduction Act of 2005, which mandates that they provide the following: objective information to help consumers decide whether to purchase long-term care insurance or to pursue other private market alternatives that pay for long-term care; information about states with long-term care insurance partnerships under the Medicaid program; and information about the availability and limitations of coverage for long–term care under the Medicaid program. For more information, contact the Centers for Medicare and Medicaid Services: www.cms.gov

Source: National Association of Insurance Commissioners: www.naic.org

Arizona Health Care Cost Containment System (AHCCCS)

The Arizona Health Care Cost Containment System (AHCCCS) is Arizona's version of Medicaid. AHCCCS provides health insurance to low income Arizonans through a health plan. Doctors, hospitals, pharmacies, etc. are included in the health plan to provide all AHCCCS covered services.

In addition to health plans, AHCCCS has several programs for seniors including:

- Medicare Cost Sharing: provides help with Medicare expenses
- SSI Cash/Medical Assistance Only: provides medical coverage for seniors who do not receive monthly cash benefits under the Supplemental Security Income Program (SSI)
- Arizona Long Term Care System (ALTCS) which provides ongoing services at nursing facility level of care either at an individual's home, assisted living facility or in a nursing home.

Medical services

AHCCCS contracts with several health plans to provide covered services. An AHCCCS health plan works like a Health Maintenance Organization (HMO). The health plan works with doctors, hospitals, pharmacies, specialists, etc. to provide care. You will choose a health plan that covers your zip code area. If you are approved, you will choose a primary care doctor that works with that health plan. Your primary doctor will:

- Be the first person you go to for care
- Authorize your non-emergency medical services
- Send you to a specialist when needed

AHCCCS health plans provide the following medical services:

- Doctor's Visits
- Immunizations (shots)
- Prescriptions (Not covered if you have Medicare)
- Lab and X-rays
- Early and Periodic Screening Diagnosis and Treatment (EPSDT) Services for Medicaid eligible children under age 21
- Specialist Care
- Hospital Services
- Transportation to doctor
- Emergency Care
- Pregnancy Care
- Surgery Services
- Physical Exams
- Behavioral Health

- Family Planning Services
- Dialysis
- Glasses (for children under age 21)
- Vision Exams (for children under age 21)
- Dental Screening (for children under age 21)
- Dental Treatment (for children under age 21)
- Hearing Exams (for children under age 21)
- Hearing Aids (for children under age 21)

Coverage for individuals eligible for Arizona Long Term Care (ALTCS)

AHCCCS contracts with several program contractors to provide long term care services. An ALTCS program contractor works like a Health Maintenance Organization (HMO). In addition to the services listed above, people who qualify for long term care can receive services such as:

- Case Management
- Nursing Home Care
- Hospice
- Attendant Care
- Assisted Living Facility
- Adult Day Care Health Services
- Home Health Services, such as nursing services, home health aide, and therapy
- Home Delivered Meals

Source: Compiled from information on the AHCCCS website www.azahcccs.gov

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Simplified Guide to ALTCS

Arizona Long Term Care System

All information is as of January 2014 and SUBJECT TO CHANGE

ALTCS is a part of AHCCCS—Arizona's version of Medicaid

ALTCS provides funding for:

- Care in a person's home
- Care in **contracted** nursing homes
- Care in **contracted** assisted living centers, assisted living homes, and adult foster care homes

General Eligibility Requirements

- Must be U.S. Citizen or have Legal Resident Status for a required period
- Must have a valid Social Security Number
- Must reside in Arizona

Medical Eligibility

Each applicant is assessed for medical eligibility using a tool called the Pre-Admission Screening (PAS). To be eligible, the individual must need a level of care equal to what is provided at an intermediate level nursing facility.

This usually includes a need for assistance with bathing, toileting, and dressing. Applicants are assessed by social workers or nurses who review medical records, conduct face to face interviews, and assess the applicant's ability to perform activities of daily living.

Generally, a family member or responsible party should be present at the interview to provide input. Applicants often try to show the assessor how well they are doing, while what is needed for eligibility is to show how incapacitated they really are. Applicants may not tell a stranger they are incontinent of bowel or bladder even if they are, and incontinence scores high on the PAS. Also, a diagnosis of Alzheimer's or other forms of dementia gives extra consideration for eligibility.

Income Eligibility

Individuals: Gross Income may not exceed **$2,163/month.**

Married Couples: If the income in the applicant's own name is less than $2,163, he or she will be income eligible. Otherwise, the couple's joint income may not exceed **$4,326/month.**

Note: If income is greater than the limits above but less than the "Average Cost of Care" ($6,648.77/month) the applicant may be able to set up a special **"Income Limiting Trust"** and be eligible. The trust must make the State of Arizona the beneficiary upon death and meet specific guidelines. (We recommend you consult with an Elder Law Attorney for this trust.)

The spouse remaining in the community may keep all income in his or her name. If the community spouse's income is less than $1,938.75/month, then he or she may be able to keep a portion of the institutional spouse's income for a total monthly income of $1,938.75.

Share of Cost

If the member is living in a facility, he or she is expected to pay a share of the cost to the facility.

For an individual the share of cost is equal to their income, less $108.15 they can keep as a "Personal Needs Allowance."

For a couple it is the individual's income less the $108.15 less the amount the community spouse is allowed by ALTCS regulation.

To Apply: Call ALTCS at (520) 205-8600

Social Security and Supplemental Security (SSI) Income Overview

To be eligible for Social Security benefits as a worker you must be:

- Age 62 or older, or disabled or blind
- "Insured" by having enough work credits

For applications filed December 1, 1996, or later, you must either be a U.S. citizen or lawfully present alien in order to receive monthly Social Security benefits.

How much work do you need to be "insured"?
We measure work in "work credits." You can earn up to four work credits per year based on your annual earnings. The amount of earnings required for a work credit increases each year as general wage levels rise.

To be eligible for most types of benefits (such as benefits based on blindness or retirement), you must have earned an average of one work credit for each calendar year between age 21 and the year in which you reach age 62 or become disabled or blind, up to a maximum of 40 credits. A minimum of six work credits is required, regardless of age.

To qualify for Social Security benefits based on a disability other than blindness, the number of work credits you need for disability benefits depends on your age when you became disabled. You generally need 20 work credits earned in the last 10 years ending with the year you become disabled. However, younger workers may qualify with fewer credits.

The rules are as follows:
Before age 24 - You may qualify if you have six work credits earned in the three-year period ending when your disability starts.
Age 24 to 31 - You may qualify if you have credit for having worked half the time between age 21 and the time you become disabled. Example: If at age 27 you become disabled, you would need 12 work credits in the past six years (between age 21 and age 27).
Age 31 and older - You must have earned at least 20 of the credits in the 10 years immediately before you become disabled.

Who can receive benefits on your earnings?
You can receive Social Security benefits based on your earnings record if you are age 62 or older, or disabled or blind and have enough work credits.

Family members who qualify for benefits on your work record do not need work credits. However, if they file an application December 1, 1996 or later, they must be a U.S. citizen or lawfully present alien. The following information describes family members who may qualify for benefits on your work record.

If you are receiving retirement or disability benefits, your spouse may qualify if he or she is:

- Age 62 and over; or
- Divorced from you, age 62 or older, and was married to you for at least 10 years prior to your divorce; or
- Under age 62 and caring for a child (under age 16 or disabled prior to age 22) who is entitled to benefits on your work record.
- If you are age 62 or over and have enough work credits to receive Social Security benefits, but have not filed a claim, your divorced spouse may qualify for benefits, if he or she was married to you for at least 10 years prior to the divorce, and has been finally divorced from you for at least two years.

Your surviving spouse (widow or widower) may qualify if he or she is:

- Age 60 or older; or
- Age 50 or older and disabled; or
- Divorced from you, age 60 or older (age 50 if disabled) and
- Was married to you for at least 10 years prior to your divorce;
- Under age 60 and caring for your child (under age16 or disabled prior to age 22) and who is entitled to child's benefits;
- Divorced from you, under age 60 and caring for his or her child (under age 16 or disabled prior to age 22) who is entitled to benefits on your record.
- A dependent parent(s), age 62 or older, of a deceased worker may qualify for benefits based on the worker's record.
- Unmarried children (including stepchildren, adopted children and, in some cases, grandchildren and children born out of wedlock) of disabled, retired, or deceased workers may qualify if they are:
- Under age 18 (or between ages 18 and 19 if a full time high school student); or
- Age18 or older and disabled before age 22.

What is SSI?

SSI stands for Supplemental Security Income. Social Security administers this program. We pay monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older. Blind or disabled children may also get SSI.

How is SSI different from Social Security benefits?

Many people who are eligible for SSI may also be eligible for Social Security benefits. In fact, the application for SSI is also an application for Social Security benefits. However, SSI and Social Security are different in many ways.

- Social Security benefits may be paid to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes.
- Unlike Social Security benefits, SSI benefits are not based on your prior work or a family member's prior work. SSI is financed by general funds of the U.S. Treasury--personal income taxes, corporate and other taxes.

- Social Security taxes withheld under the Federal Insurance Contributions Act (FICA) or the Self Employment Contributions Act (SECA) do not fund the SSI program.
- In most states, SSI beneficiaries also can get medical assistance (Medicaid) to pay for hospital stays, doctor bills, prescription drugs, and other health costs.
- In most states, SSI beneficiaries also can get medical assistance (Medicaid) to pay for hospital stays, doctor bills, prescription drugs, and other health costs. Most states also provide a supplemental payment to certain SSI beneficiaries.
- SSI beneficiaries may also be eligible for food assistance in every state except California. In some states, an application for SSI benefits also serves as an application for food assistance.
- SSI benefits are paid on the first of the month.
- To get SSI, you must be disabled, blind, or at least 65 years old and have "limited" income and resources.
- In addition, to get SSI, you must:
    - be a resident of the United States, and
    - not be absent from the country for a full calendar month or more or for 30 consecutive days or more; and
    - be either a U.S. citizen or national, or in one of certain categories of qualified non–citizens.

How is SSI like Social Security benefits?

- Both programs pay monthly benefits.
- The medical standards for disability are the same in both programs for individuals age 18 or older. For children from birth to age 18 there is a separate definition of disability under SSI.
- SSA administers both programs.

Source: Social Security Administration. See www.ssa.gov for more information

VA Non-Service Connected Pension with Aid & Attendance (Improved Pension)

This is a benefit for Veterans or Surviving Spouses who meet eligibility requirements regarding (1) military service, (2) net worth limitations and (3) disabilities and level of care. The final eligibility consideration is (4) income. The purpose of this benefit is to provide some financial assistance when a veteran's (or surviving spouse's) health declines and their medical expenses increase. When a person qualifies for this benefit, the VA considers all sources of income and deducts eligible medical expenses to calculate countable income. The VA then supplements income to bring it back up to income levels as set by Congress.

(1) Military Service Requirements:

Veteran with 90 days active duty*, one day beginning or ending during a period of war. A surviving spouse of a War Veteran must have been married to the veteran at the time of veteran's death. Cannot have a dishonorable discharge.

(2) Household Net Worth/Asset Limitations:

Based on Household Net Worth/Asset Limitations: See Life Expectancy Chart Versus Rate of Spending Down Net Worth/Assets. This benefit is not intended to preserve an inheritance for heirs. **(The primary residence is excluded as well as primary vehicle)**

(3) Disabilities/Level of Care:

Require regular attendance of another person to assist in eating, bathing, dressing/undressing or taking care of the needs of nature. It also includes individuals who are blind or patients in a nursing home because of mental or physical incapacity. Assisted care in an assisted living facility may also qualify.

(4) Household Income Limitations:

Single Veteran	$1,758.91
Surviving Spouse	$1,130.25
Married Veteran	$2,085.16

How long is the application process?

To actually begin receiving payment from the VA takes an average of 6 to 8 months. However, the VA does pay retroactively to the date they receive the application.

War Time Service:

WWII	12/07/1941 through 12/31/1946
Korean War	06/27/1950 through 01/31/1955
Vietnam War	08/05/1964 through 05/07/1975 **
Gulf War	08/02/1990 through (yet to be determined) *

Example:

Total monthly income:		$2,700.00	
Total out- of -pocket medical expenses	-	$2,400.00	
Net income (income – medical expenses)		$300.00	***
Maximum pension benefit with aid and attendance		$1,758.91	****
Less total net income	-	$300	***
Total VA benefit per month		$1,458.91	

How do I apply?

In order for the VA to determine eligibility you must submit the appropriate VA application for pension with the following documents: DD-214 or separation papers, medical evaluation from physician showing current medical issues, net worth and net income along with out of pocket medical expenses (to include expense for assisted living or nursing home care). Surviving spouse must provide death certificate of veteran and proof of marriage.

Free Application Assistance

The Arizona Department of Veteran Services (ADVS) has service officers available to answer questions, complete applications and provide assistance throughout the claims process. For information please call the Tucson ADVS office at (520) 207-4960.

VA Pension website: http://www.vba.va.gov/bln/21/pension/vetpen.htm

NOTES:

*Veterans of Gulf War must serve minimum of 24 months

** Veterans who served in Vietnam as early as 02/2/1961 are also war time veterans.

*** The VA may allow for medical expenses to be deducted from income reducing income to as low as $0.

****Total income minus medical expenses must be less than the maximum award.

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Glossary of Health Insurance Terms

Accountable Care Organizations - An Accountable Care Organization is a network of doctors, hospitals, and other providers that shares responsibility for providing care to patients. In the Affordable Care Act, an Accountable Care Organization would agree to manage all of the health care needs of a minimum of 5,000 Medicare fee-for-service beneficiaries for at least three years.

Advance Coverage Decision - A decision that your Medicare Private Fee-for-Service Plan makes on whether it will pay for a certain service.

Affordable Care Act - *Patient Protection and Affordable Care Act of 2010* signed into law March 23, 2010 and *The Health Care and Education Reconciliation Act of 2010* signed into law March 30, 2010 together form the Affordable Care Act which addresses health care reform.

Appeals Process - The process used if a beneficiary disagrees with any decision about his or her health care services. If Medicare or a Medicare health plan does not pay for an item or service received or if a service was not provided, the initial Medicare decision can be reviewed.

Assignment - An agreement between a person with Original Medicare, a doctor or supplier, and Medicare. The person with Medicare agrees to let the doctor or supplier request direct payment from Medicare for covered Part B services, equipment, and supplies. Doctors or suppliers who agree to (or must by law) accept assignment from Medicare can't try to collect more than the Medicare deductible and coinsurance amounts from the person with Medicare, the person's other insurance (if any), or from anyone else. If you are in the Original Medicare Plan, it can save you money if your doctor, provider, and supplier accept assignment.

Balance Billing - A situation in which Medicare Private Fee-for-Service Plan providers (doctors or hospitals) can charge and bill up to 15% more than the plan's payment amount for services.

Benefit Period - The way Medicare measures your use of hospital and skilled nursing facility (SNF) services. A benefit period begins the day you go to a hospital or skilled nursing facility. The benefit period ends when you haven't received any hospital (or skilled care in a SNF) for 60 days in a row. If you go into the hospital after one benefit period has ended, a new benefit period begins. You must pay the inpatient hospital deductible for each benefit period. There is no limit to the number of benefit periods you can have.

Beneficiary - The name for a person who has health insurance through the Medicare or Medicaid (AHCCCS) program.

CMS - Centers for Medicare and Medicaid Services (formerly HCFA-Health Care Financing Administration).

Coinsurance - Sometimes called a "copayment," it is the percentage of your covered medical bills that you pay after your annual deductible has been met, and your insurance plan has paid its portion of the bills. For example, on a standard 80/20 coinsurance plan, the insurance company will pay 80 percent of the covered expenses and you, the insured, will pay 20 percent.

Coordination of Benefits - Insurance company's method of coordinating your payment when you have similar coverage with more than one insurance company. This happens when you have two major medical plans (e.g., Medicare and an employer major medical). Only one plan will pay 80% of the charges. You will not receive duplicate coverage for the same services. Unlike a supplemental insurance, your second major medical may not pay the remaining balance after your first major medical insurance has paid.

Creditable Prescription Drug Coverage - Prescription drug coverage (like from an employer or union), that pays out, on average, as much as or more than Medicare's standard prescription drug coverage.

Custodial Care - Care is considered custodial when it is primarily for the purpose of helping you with daily living or meeting personal needs and could be provided safely and reasonably by people without professional skills or training. Much of the care provided in nursing homes to people with chronic, long-term illnesses or disabilities is considered custodial care. For example, custodial care includes help in walking, bathing, eating, and taking medicine. Even if you are in a hospital or skilled nursing facility, insurance usually does not provide coverage for custodial care.

Copayment - A predetermined fee that you pay directly to the doctor or other healthcare provider when you receive services.

Deductible - The amount of covered expenses that the insured must pay in each benefit period before the insurer pays for allowable claims. A higher deductible will usually result in a lower premium.

Deemed - Providers are "deemed" when they know, before providing a service, that you are in a Medicare Private Fee-for-Service Plan; they have reasonable access to the plan's terms and conditions of payment; and the service is covered by the plan. Providers that are "deemed" agree to follow your plan's terms and conditions of payment for the services you get.

Diagnosis Related Groups (DRG) - Illness/inpatient admission categories established by Medicare and used by hospitals to determine payment under the Prospective Payment System.

End-Stage-Renal Disease (ESRD) - Permanent kidney failure requiring dialysis or a kidney transplant.

Fee-For-Service - You (or your insurance) are charged for each visit or service provided by a physician or other healthcare professional.

Formulary - A list of certain kinds of prescription drugs that a Medicare drug plan will cover subject to limits and conditions and which will be dispensed through participating pharmacies to covered enrollees.

Grievance - Complaints about the way a Medicare health plan provides care (other than complaints about providing a service or payment for a service), such as cleanliness of the health care facility, problems calling the plan by phone, staff behavior, or operating hours.

Health Care and Education Reconciliation Act of 2010 - Legislation signed into law March 30, 2010 which addresses health care reform along with the *Patient Protection and Affordable Care Act of 2010* signed into law March 23, 2010 - together referred to as the *Affordable Care Act*.

Health Maintenance Organization Plan (HMO) - A type of Medicare Advantage Plan that must cover all Medicare Part A and Part B health care. Some HMO's cover extra benefits, like extra days in the hospital. In most HMO's, you can only go to doctors, specialists, or hospitals on the plan's list except in an emergency. Your costs *may* be lower than in the Original Medicare Plan.

Home Health Care - Home healthcare services are given at home to aged, disabled, sick or convalescent individuals who do not need institutional care. The most common types of home care are visiting nurse services (e.g. IV therapy, wound care, medication administration), and speech, physical, occupational, and rehabilitation therapy. Home health agencies, hospitals or other community organizations provide these services.

Hospice Care - Hospice care for the terminally ill (e.g. end stage cancer, emphysema, heart disease, or renal disease) and their families, in the home or a non-hospital setting, emphasizing alleviating pain rather than medical cure.

Hospitalist - A doctor who specializes in the care of patients who are in the hospital. A hospitalist might be an internal medicine doctor or a specialist. The best example of a doctor who has a role like a hospitalist is the emergency room (ER) doctor.

Indemnity - An indemnity is a benefit paid by an insurance policy for a specific illness, injury or hospitalization. Often it is used to refer to benefits paid directly to the insured. An example would be a policy that pays you $75 for every day you are confined to a hospital. Accident policies, income policies, and cancer policies are types of indemnity plans. Major medical is another type of indemnity policy.

Insurance Department - Each state has an insurance department that is responsible for implementing state insurance laws and regulations. The Arizona Department of Insurance can be reached at (602) 364-2499 or (800) 325-2548. They also handle complaints about insurance companies.

Limitations - Limitations describe conditions or circumstances under which the insurer will not pay or will limit payments. Detailed information about limitations and exclusions are found in your insurance policy. For example, if you have a pre-existing condition for which you have been diagnosed, received treatment, or incurred expenses for prior to your insurance coverage eligibility, you may not be covered by your insurance for a specific amount of time.

MA-PDP's - Medicare Advantage-Prescription Drug Plans sold in conjunction with the medical health plans under Medicare Advantage. The coverage can be through an HMO (Health Maintenance Organization), PPO (Preferred Provider Organization), or a PFFS (Private Fee-for-Service Plan).

Major Medical - Major medical insurance plans provide broad coverage and substantial protection from large, unpredictable medical care expenses. Members are usually responsible for deductible and coinsurance amounts.

Maximum Out-of-Pocket Liability - The maximum amount of money an insured will pay in a benefit period, in addition to regular premium payments is called the maximum out-of-pocket. It is usually the sum of deductibles and coinsurance payments that the policyholder must pay before the insurance company pays 100% of the covered expenses. Non-covered expenses are the policyholder's responsibility in addition to out-of-pocket amounts.

Medical Underwriting - The process that an insurance company uses to decide whether or not to take your application for insurance, whether or not to add a waiting period for pre-existing conditions, and how much to charge you for that insurance.

Medically Necessary - Services or supplies that meet all of the following:

- Are proper and needed for the diagnosis or treatment of your medical condition.
- Are provided for the diagnosis, direct care, and treatment of your medical condition.
- Meet the standards of good medical practice in the local area.
- Are not mainly for the convenience of you or your doctor.

Medicare Advantage Plan - A plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A and Part B benefits. In most cases, Medicare Advantage Plans also offer Medicare prescription drug coverage. Medicare Advantage (formerly Medicare + Choice or Part C) Plans include:

- Medicare Managed Care Plans (HMO)
- Medicare Managed Care Plans w/POS (Point of Service)
- Medicare Preferred Provider Organization Plans (PPO)
- Medicare Private Fee-for-Service Plans (PFFS)
- Medicare Specialty Plans (Special Needs)
- If you have one of these plans, you don't need a Medigap policy.

Medicare Administrative Contractors (MAC's) - A single point of contact. The MAC's process both Part A and Part B claims which reduces duplication of activities.

Medicare Approved Cost (MAC) - A doctor and supplier fee schedule that lists payments for each Part B service. The fee schedule takes into account geographic variation for practice costs. The MAC is the lower of either the Medicare fee schedule amount, or the doctor's/suppliers actual charge.

Medicare SELECT - A type of Medigap policy that may require you to use hospitals and, in some cases, doctors within its network to be eligible for full benefits.

Medicare Summary Notice (MSN) - After Medicare pays a claim, Medicare sends the patient a MSN notice. This notice is not a bill. It provides information for patient records on the services they received.

Medigap - A Medicare supplemental health insurance policy sold by private insurance companies to fill "gaps" in Original Medicare Plan coverage. Except in Minnesota, Massachusetts, and Wisconsin, there are 10 standardized policies labeled Plan A, B, C, D, F, G, K. L, M, and N. Medigap policies only work with the Original Medicare Plan. Plans E, H, I, and J were no longer sold after June 1, 2010—existing policies were grandfathered.)

Medigap High-Deductible Option Plan - Insurance companies may offer a "high deductible option" on Medigap Plans F and J. If you choose this option, you must pay a $2,070 deductible for the year 2012 before the policy pays anything. This amount can go up each year. In addition to the $2,070 deductible (in 2012) that you must pay for the high-deductible option for Plans F and J, you must also pay separate deductibles for

- Foreign travel emergency ($250 per year for Medigap Plans F and J), and
- Prescription drugs ($250 per year for Medigap Plan J only, because Medigap Plan F doesn't cover prescription drugs). This only applies to Medigap policies bought before January 1, 2006. Medigap policies sold after this date can't include prescription drug coverage.

Original Medicare Plan - A fee-for-service health plan that lets you go to any doctor, hospital, or other health care provider who accepts Medicare. You must pay any applicable deductible. Medicare then pays its share of the Medicare-approved amount, and you pay your share (coinsurance). The Original Medicare Plan has two parts: Part A (Hospital Insurance) and Part B (Medical Insurance).

Outpatient Services - A service you get in one day (24 hours) at a hospital or community health center.

PDP's - Medicare Prescription Drug Plans - A stand-alone drug plan, offered by insurance and other private companies to add prescription drug coverage to the Original Medicare Plan, and Medicare Private Fee-for-Service Plans that don't have prescription drug coverage.

Patient Protection and Affordable Care Act of 2010 - Legislation signed into law March 23, 2010 which addresses health care reform along with *The Health Care and Education Reconciliation Act of 2010* signed into law March 30, 2010 - together referred to as the *Affordable Care Act*.

Point of Service - A POS Plan consists of several different options of insurance coverage that the participant can choose from at the time healthcare services are sought - going out of network for some services (higher costs will apply). The plan provides financial incentives for using network providers.

Preferred Provider Organization Plan (PPO) - A type of Medicare Advantage Plan in which you pay less if you use doctors, hospitals, and providers that belong to the network. You can use doctors, hospitals, and providers outside of the network for an additional cost.

Private Fee-for-Service Plan (PFFS) - Private fee-for-service is a type of Medicare Advantage Plan in which you may go to any Medicare-approved doctor or hospital that accepts the plan's payment. The insurance plan, rather than the Medicare Program, decides how much it pays and what you pay for the services you will get. You may pay more or less for Medicare-covered benefits. You may have extra benefits the Original Medicare Plan doesn't cover.

Prospective Payment System - Hospitals, Skilled Nursing Facilities, Home Health Agencies and Hospice are paid a set rate based on payment categories. In some cases the Medicare payments are more than the actual costs; in other cases, less than the actual costs. Even if Medicare pays less than the cost of care, the beneficiary does not have to make up the difference.

Quality Improvement Organization (QIO) - Groups of practicing doctors and other health care professionals paid by the federal government to monitor care given to Medicare patients. Each state has a QIO with the authority to decide whether care given to Medicare patients is reasonable and necessary, provided in the most appropriate setting and meets standards of quality generally accepted by the medical profession.

Reasonable and/or Customary Charge - Healthcare service charges that are determined by comparing similar services in a specific geographic area.

Special Needs Plan - A special type of plan that provides more focused health care for specific groups of people, such as those who have both Medicare and Medicaid (AHCCCS - Arizona Health Care Cost Containment System), those with a chronic health condition, or those who reside in a nursing home.

Supplemental Insurance - See Medigap Insurance.

TRICARE for Life - A joint program between Medicare and the Department of Defense to provide military retirees, qualifying family members and survivors, and certain former spouses, medical and prescription benefits exceeding the limitations of the Medicare Program.

Unassigned Claim - If a physician/supplier doesn't agree to accept the Medicare approved charge, as the total charge, it is called an unassigned claim. In this case, the beneficiary pays the doctor or supplier. Medicare reimburses the beneficiary 80% of the approved amount after subtracting any part of the Part B annual deductible which has not been met.

Source: Pima Council on Aging - Medicare/Health Insurance Assistance Program

Section 9

Health-Related Issues

PCOA
PIMA COUNCIL ON AGING
Advocacy, Action, Assistance

Medical Visits:
Scheduling, Preparation and Support

Helping older relatives or friends to become active participants in their own health care.

Frequently Asked Questions about Helping Relatives with Medical Visits

As a caregiver, you can provide valuable assistance in accompanying your relative to medical visits. You can provide companionship and support while your loved one waits to see the doctor, mention concerns that your relative may have forgotten to ask, and record what is said by the doctor for your relative to review later.

How can I assist my relative in preparing for initial visits with a physician?

If your loved one is meeting a doctor for the first time, suggest that he or she bring the following information:

- The names, addresses and telephone numbers of all health professionals he or she has seen recently along with the dates of service that are most significant in your relative's medical history.
- A list of the names and dosages of current medications, including over-the-counter drugs and supplements. (Another option is to put all the medications in a bag and bring them to the appointment.)
- The name, location, and phone number of your relative's pharmacy.
- The names and telephone numbers of emergency contacts.
- A list of food and drug allergies.
- Medicare and/or health insurance cards. (Make sure your relative's coverage is accepted by a particular physician before making the appointment.)
- Copies of advance directives, if any, including: living will, health care power of attorney and any other pre-hospital directives. Your relative's primary physician, specialist and hospital should all have a copy of any advance directives.

Help your loved one prepare a brief description of his or her current symptoms that includes when each first appeared, the severity, what makes the symptoms better or worse and what, if any, self-treatment your relative has tried at home.

Be aware that your relative may be uncomfortable about openly discussing sensitive topics such as sexuality, incontinence or memory problems with you as well as the doctor. Remember to always respect how much your relative is willing to share with you about his or her health condition(s). If you are your relative's designated health care agent (health care power of attorney), you may want to inform the physician about your relative's concerns prior to the visit.

What should my relative learn about the physician's routine and medical office protocol to improve access to care when needed?

It is important for your relative to become familiar with the physician's routine and office protocol in order to obtain timely care and information. Your relative may consider asking the office manager or other administrative staff the following questions:

- What are normal office hours? Most doctors are not available 24 hours a day, seven days a week so it is important that your relative find out who to call after hours or who is available to answer questions if the doctor is away.
- Are walk-ins seen? If urgent care is needed, can your relative be seen within 24 hours? If routine care is needed, can your relative be seen within a week? Is there a penalty fee for no-shows or cancellations? What is the typical length of time reserved for a routine office visit?
- What is the best time to make routine, non-urgent phone calls?
- If 911 has been called in a medical emergency, how and when will the physician be notified?
- Who should your relative call if he or she has questions about a treatment, procedure or side effects from a prescribed medication?
- Who will have a current copy of your relative's medical file, including information about your relative's conditions, medications and treatment plan?

How can I help my relative on the day of the medical visit?

On the day of the medical visit, make sure your relative is as relaxed as possible and feels "in control." If you will be accompanying your relative, you may want to arrive at your relative's residence at least one hour prior to the required travel time to the physician's office. This extra time will give both you and your relative a chance to review the reasons for the visit, talk about expectations and prioritize the three most important concerns to be addressed. This will also allow for extra time if you are unfamiliar with the location of the medical office or if your relative has mobility issues.

Ask how you can be of most help during the medical visit, i.e., what your relative would like and not like you to do.

Can I discuss my relative's health condition with the physician and other health professionals?

Your relative must specify who is authorized to have access to his or her medical information. An individual has certain rights under federal privacy standards about how his or her medical information may be used and made known to others, including:

- The right to restrict the use and disclosure of protected health information.
- The right to receive confidential communications concerning his or her medical conditions and treatments.
- The right to inspect and copy his or her protected health information.
- The right to an accounting of how and to whom protected health information has been disclosed.

If you are the designated health care agent (health care power of attorney) for your relative, then you have authorization to discuss your relative's health condition with treating physicians and other health care practitioners. If you are not the designated health care agent, your relative must tell treating physicians and other practitioners that you may talk to them about his or her medical condition and treatment.

Should my relative always speak directly with the physician regarding any health concern?
Your relative may not always need to talk to the physician directly about basic questions. The doctor's nurse, nurse practitioner or physician's assistant may have more availability and more time to spend answering questions. Remember, the doctor's staff can look up information in your relative's medical file and consult with the doctor as needed. However, if your relative wants to speak to the doctor directly, he or she has the right to make that request.

Some practical considerations include:
- Ask the office receptionist when would be the best time to reach the doctor. Some doctors have specific hours when they take calls. Find out what these times are and call then.
- Your relative may want to ask if it is possible to communicate with the physician via e-mails about non-urgent health concerns.

What should my relative say when contacting the physician about a health problem?
Some general guidelines that your relative should follow when calling the physician about a health concern are:
- Be prepared before calling. Have your relative write down a short description of the problem, the reason for calling, a short symptom list and no more than three questions to ask the physician.
- Be concise and stick to the issues.
- If your relative does not understand something, ask the doctor to explain it again, possibly in a different way that will be clearer to your relative.

Time and again, the doctor or the doctor's staff does not return my relative's telephone calls. What can my relative do to make sure the doctor or doctor's staff responds in a timely manner?
Depending on the type of relationship your relative has with the doctor, he or she may want to consider changing doctors. If your relative has formed a trusting and long-standing relationship with the doctor, working out the problem may be more useful than looking for a new doctor. Misunderstandings arise in any relationship, including between patient and doctor. Suggest that your relative be direct when speaking to the doctor or the doctor's staff about the problem. For example, your relative may want to say something like, "I realize that you are very busy and take care of a lot of patients, but I get upset and frustrated when I have to wait for days for you to return my call. How can we solve this problem?" If the doctor or doctor's staff continues to brush off your relative's concerns, then it may be in your relative's best interest to look for another doctor.

Pathfinder: Medical Visits FAQs   Revised 06/2014

Communicating with Physicians and Other Health Professionals

Helping older relatives or friends to become active participants in their own health care.

Frequently Asked Questions about Communicating with Health Professionals
In your caregiver role, it is important to support and encourage your relative in effectively communicating with physicians and other health professionals. Your relative may not be willing to share as much about his or her health conditions with you as you would like. Respectfully acknowledging your relative's right to privacy and to make his or her own decisions can improve communication. It may also be helpful to ask what assistance he or she would prefer from you.

If your relative is unable to understand or follow a physician's directions you will need to become more directly involved. If your relative is willing to have assistance, he or she can simply inform the physician that he or she wishes information to be shared with you and wishes you to be present at appointments. If your relative is showing symptoms of dementia, you may want to contact the physician privately and inform him or her (verbally or in writing) about what you have observed and ask that your relative be thoroughly evaluated. If your relative has been diagnosed with dementia and is not willing to accept your assistance, you may need to invoke a Health Care Power of Attorney, if you relative has previously completed this document.

What are the major communication barriers between older patients and physicians?
An older person is less likely to ask questions of health care providers and more likely to "follow doctor's orders," even if he or she doesn't understand the purpose behind a particular treatment, test or medication. He or she may prefer to rely on the doctor's expertise rather than become involved in the decision-making process.

Another problem may be that your relative does not have as much time with the doctor as he or she would like. In a busy medical practice, your relative may feel rushed and be reluctant to ask the doctor to spend extra time answering questions. Or your relative may simply feel too intimidated to ask questions or request additional time with the doctor.

Communication problems can also arise when a caregiver accompanies an older person on a medical visit. In this situation, it is not uncommon for the doctor or doctor's staff to speak solely to the caregiver and not the patient. This may make the older person feel invisible, powerless over decisions about his or her own health care, and reluctant to participate in the discussion.

An older person may also feel that ill health is a normal part of aging rather than something that can and should be treated.

In cases where a lot of information is imparted by the doctor, an older person may find it difficult to remember much of what was said. It may help to take notes or have a caregiver present.

How can I help my relative take a more active role in talking with the physician?

Speak to your relative about viewing the relationship with the physician as a “partnership” where both partners share information to achieve the best possible care. For the older person, being a good partner means taking care of oneself, practicing self-care at home, writing down symptoms at the first sign of a health problem, and playing an active role during the medical visit by asking questions and discussing one’s own preferences for care. This includes asking for clarification if the doctor’s explanations or instructions are unclear, bringing up problems even if the doctor doesn’t ask about them, and letting the doctor know if a treatment isn’t working.

When considering the doctor’s role in the partnership, you and your relative may want to determine whether or not the doctor listens carefully to concerns, explains things clearly and fully, offers reassurance when appropriate, and whether the doctor or his staff return phone calls in a timely manner.

You can help your relative by writing down a list of questions and concerns prior to any medical appointment. Some questions that your relative may want to ask:

- What illness do I have?
- What are my treatment options?
- What should I expect to happen with treatment? And if I decline treatment?
- Will my insurance cover the entire cost of the treatment?
- Where can I get additional information about the illness, treatment or medication?

Are there communication tips that will help prepare my relative for a medical visit?

You may want to discuss with your relative the following tips for talking to the doctor:

- **Be honest.** Resist the temptation to tell the doctor what he wants to hear, and instead tell him what is going on. If the doctor previously recommended a low-fat diet and your relative has declined to follow that advice, it is best to tell the doctor the truth. Tell the doctor exactly what is going on, both physically and emotionally.
- **Stick to the point.** Your relative can make the best use of time by giving the doctor a brief description of his or her symptoms and when they started, how often they occur, and if they are getting worse or better. If your relative has a lot of concerns or questions, suggest that he or she request extra time with the doctor when scheduling the next medical appointment.
- **Ask about alternatives to conventional treatment.** Many common conditions, if not very serious, can be treated without medications. The doctor may recommend that your relative first consider trying exercise, good nutrition, stress reduction methods, and other therapies to alleviate symptoms.
- **Learn more about medical tests and other procedures.** The doctor may order blood tests, x-rays or other procedures that will help identify an illness or suggest treatment options. Suggest that your relative ask the doctor to explain why the test or procedure is important, what it will cost, whether a follow-up visit will be needed, and if he or she needs to fast or avoid medications prior to the test or procedure. Remind your relative to ask who will receive the results of the test and when.

- **Ask the doctor about the diagnosis and what to expect.** Your relative may want to ask the doctor the following questions: What may have caused the condition? Will it be permanent? How is the condition treated or managed? What will be the long-term effects on my life? How can I learn more about my illness or condition?
- **Ask for clarification.** If your relative does not understand something, ask the doctor to explain it again. Repeating what was stated may help your relative hear it correctly.

Pathfinder: Communicating with Doctors Revised 06/2014

Mending Medicine Mayhem

As people age they tend to develop medical conditions, such as high blood pressure, diabetes and arthritis that may require medications to stay healthy. Recent studies have shown that an individual over age 65 may take between two and seven prescription medications daily. The increased number of medications is related to the higher likelihood of having an adverse reaction or complication. That is why it is so important to understand the medications one takes, what they are for, and how to use them safely.

Follow directions – Physicians prescribe new medications for a specific medical purpose. Each medication should always be taken as directed. A medication may not work if taken in the improper amount or at the wrong time. Taking the prescribed dose is also important. Taking less than prescribed may mean the drug may not do what is intended. Taking more than prescribed can result in side effects. In the case of antibiotics prescribed for an infection, missing doses in the course of treatment may not fully eliminate the illness-causing bacteria.

Stick with one pharmacy – If possible, try to use the same pharmacy for all prescriptions. When the pharmacist knows all the medicines an individual takes, it is easier to check for errors and duplications. Whether you are picking up a new prescription or a refill, always check the patient name, drug name and dosage on the bottle. Note special instructions about side effects (such as sleepiness) or whether the medication can be taken with certain foods or alcohol. If you have any questions, ask the pharmacist before you leave.

Avoid confusion – Don't wait until the medication is empty to call the doctor or pharmacy for a refill. Be sure to keep medications in the container they came in to avoid errors or mixing medicines.

All medications matter – Remember that over-the-counter drugs can interact with prescribed medicines, food or alcohol. Some common over-the-counter medicines include treatments for heartburn and digestive problems such as diarrhea and constipation; cold, flu and allergy remedies; and pain relievers such as aspirin, acetaminophen (e.g., Tylenol) and ibuprofen (e.g., Motrin, Advil). These drugs can be very helpful when used properly, but can cause serious problems if used incorrectly. Always consult the pharmacist for help in finding the most appropriate over-the-counter drug.

Source: Dr. George Louie, MD
Medical Director, SCAN

Making Smart Food Choices

Regular physical activity and a healthy diet go hand in hand. *Go4Life* points you to wise food choices important for good health: eat a variety of healthy foods, fill up half of your plate with fruits and vegetables, and limit solid fats and added sugars.

The Dietary Guidelines for Americans suggest you:

- Try to choose grain products made from whole grains.
- Vary your veggies. Brighten your plate with vegetables that are red, orange, and dark green.
- Eat more fruit. Try some you haven't eaten before.
- Choose lean meats, poultry, seafood, beans, eggs, and nuts.
- Choose low-fat or fat-free dairy products.
- Get plenty of fluids each day such as water, fat-free or low-fat milk, and low-sodium broth-based soups.
- Limit saturated fats, trans fats, cholesterol, salt, and added sugars.

Some tips to help you get started:

- Breakfast is a good time to enjoy foods with fiber. Try unsweetened, whole-grain, or bran cereals and add fruit such as berries and bananas.
- Snack on unpeeled apples, pears, and peaches. Don't forget to rinse them before eating.
- Season foods with lemon juice, herbs, or spices.
- Broil, roast, bake, steam, microwave, or boil foods instead of frying.
- Use oils instead of solid fats, like butter, when cooking.
- Read *What's On Your Plate?*, the National Institute on Aging guide to healthy eating. Order your free copy at www.nia.nih.gov.

✓ *Quick Tip*

To maintain a healthy weight, balance the calories you take in from food and beverages with the calories burned through physical activity.

VISIT

www.nia.nih.gov/Go4Life

- Read more tips for adding physical activity to your day.
- Print useful tools.

National Institute on Aging
National Institutes of Health
U.S. Department of Health & Human Services

Overcoming Roadblocks to Healthy Eating

Sometimes it's hard to make smart food choices. Here are some suggestions from *Go4Life* to help you overcome barriers to healthy eating.

Does food taste different? Your sense of taste or smell can change with age. Medication side effects and other things also can affect these senses. Try using lemon juice, vinegar, or herbs to boost the flavor. Ask your doctor whether your medications affect taste and about food and drug interactions.

Do you have problems chewing food? People who have problems with their teeth or dentures often avoid eating meat, fruits, or vegetables and might miss out on important nutrients. If you're having trouble chewing, see your dentist to check for problems. If you wear dentures, ask your dentist to check how they fit.

Is it sometimes hard to swallow food? If food gets stuck in your throat, less saliva in your mouth might be the culprit. Drinking plenty of liquids with your meal might help. Talk to your doctor about the problem.

Are you just not hungry? Try being more active. In addition to the other benefits of exercise, it may make you hungrier. Lack of appetite sometimes is a side effect of medication—your doctor might be able to suggest a different drug. If food just isn't appealing, vary the shape, color, and texture. Look for a new vegetable, fruit, or seafood you haven't tried before.

Are you tired of cooking or eating alone? Try cooking with a friend to make a meal you can enjoy together. Look into eating at a nearby senior center, community center, or religious facility. You'll enjoy a free or low-cost meal and have some company while you eat.

✓ ***Quick Tip***

For more ideas on healthy eating, read *What's on Your Plate? Smart Food Choices for Healthy Aging.* **www.nia.nih.gov/health**

VISIT
www.nia.nih.gov/Go4Life

- Find tips for adding physical activity to your day.
- Print useful tools.
- Share your exercise story.

National Institute on Aging
National Institutes of Health
U.S. Department of Health & Human Services

Senior Oral Health Issues

Older patients are at greater risk for oral and general health problems because of declining physical and/or mental status, medications and not understanding the importance or not being able to afford routine dental care. Common teeth, mouth and other health related problems that may affect oral health:

- Dry mouth is caused by a reduced saliva flow, which can be caused by cancer treatments that use radiation to the head and neck area, as well ascertain diseases, such as Sjogren's syndrome, and certain medications. The lack of saliva can cause uncontrolled bacterial growth that leads to tooth and root decay (cavities) and certain gum infections. Denture wearers may have more problems with the fit of their denture or with sores in their mouths when they have dry mouth.
- Root decay is a cavity caused by acids from bacteria (plaque) left at the gum line. The root surface is more likely to decay as the gum tissue recedes from the tooth. These cavities can often be prevented and are usually worse in people with dry mouth.
- Malnutrition (poor nutrition) can be caused by not being able to eat healthy and crunchy fresh foods. Some of the causes may be dry mouth, broken, decayed teeth and painful gums caused by periodontal (gum) disease and poor-fitting dentures.
- Diminished sense of taste is caused by a natural age-related decrease in the sense of taste and smell. Dry mouth, diseases, medications and dentures can contribute.
- Oral cancer is most commonly found on or under the tongue and sometimes includes the surrounding jawbones and glands of the head and neck. Prevention and early detection are very important! A yearly oral exam by a medical or dental professional is recommended.
- Oral mucositis is a common side effect of cancer treatment that causes inflammation and sores inside of the mouth. A dental exam is necessary before starting cancer therapy to lessen the oral problems that may develop.
- Diabetes is a very common disease. Many people with diabetes do not even know they have the disease. There are many ways to help to control diabetes and to lessen the damage it causes to different parts of the body(i.e. eyes, heart, feet and mouth). Gum infections have been called the sixth complication of diabetes, because people with diabetes are more likely to have periodontal (gum and bone) disease. People with diabetes and periodontal disease also have a more difficult time controlling their blood sugar.
- Periodontal (gum and bone) disease is an infection of the gum and/or bone that hold the teeth in place. The disease is caused by a buildup of plaque(invisible, soft and sticky bacteria) and can be made worse by food left in teeth, use of tobacco products, poor-fitting bridges and dentures, poor diets and certain diseases, such as anemia, cancer and diabetes.
- Gingivitis is a type of gum infection with red and bleeding gums. At early stages the infection can be reversed with proper treatment and daily oral hygiene care.
- Periodontitis is an infection in the mouth that causes bone to break down (lose bone) around the teeth. A dental exam will show how much damage (bone loss) has been done.
- Osteoporosis may make the bone in the jaw more likely to be destroyed by periodontal disease.

- Thrush is an overgrowth of a fungus in the mouth. It appears as a white area or patch in the mouth or sores at the corners of the mouth. Diseases or medications that affect the immune system can trigger the overgrowth of fungus. An oral exam and treatment is necessary to try to control the fungus.
- Denture-induced stomatitis is an inflammation of the gums and/or roof of the mouth under a denture where the tissue looks very red. Poor fitting dentures, poor dental hygiene, a buildup of bacteria or an oral fungus can cause the condition. An oral exam and treatment may correct the problem.
- Acid reflux is the production of excessive stomach acid that flows up into the esophagus and can come up into the mouth and eat away at the teeth and irritate the gums, throat and mouth. Rinsing the mouth after acid reflux is one way to help lessen the damage of acid on teeth and the rest of the mouth.
- Respiratory infections (pneumonia) have been associated with breathing in bacteria (germs) from unhealthy mouths. This connection between the bacteria in the mouth and in the lungs has been seen in nursing home patients who may not be as healthy overall.
- Menopausal or post-menopausal women may notice changes in their mouths. Dry mouth, bleeding gums, burning feeling in the gums and altered taste are oral changes that might occur with hormone changes. Recent studies found women with low estrogen levels are more likely to have periodontal disease (gum and bone infection) and tooth loss.
- Increased risk of heart disease and stroke in people with gum infections has been found in recent studies. However, there is not yet enough evidence to say for sure that oral infections are a cause of heart disease or stroke.

Source: Oral Health Care Concerns Preventive Guidelines & Techniques for Seniors and Caregivers. United Way of Tucson and Southern Arizona and the Alliance of the American Dental Association, ©2005

Know When You Need Medical/Dental Help – Oral Assessment Guide

Adapted from the University of Iowa Gerontological Nursing Interventions Research Center

Category	Healthy	Changes	Unhealthy	What to do
Lips	smooth, moist	dry, chapped or red at corners	swelling or lump, white/red/ ulcer patch, bleeding or ulcers at corners	Changes or Unhealthy = see medical or dental professional
Tongue	moist, roughness, uniform color	patches, deep grooves, red, coated	patch that is red and/or white, ulcers or swollen	Changes or Unhealthy = see medical or dental professional
Gums and Tissues	moist, smooth, not red	dry, shiny, rough, red, swollen, ulcer or sore spot under dentures	swollen, bleeding gums, ulcers/ white or red patches, redness or ulcers under dentures	Changes or Unhealthy = see dental professional
Saliva	moist tissues (tongue, cheeks), watery and free flowing	dry and sticky tissues, little saliva present	tissues dry and red, very little or no saliva present or very thick saliva	Changes = see medical or dental professional Unhealthy = see dental professional
Natural Teeth	no cavities on tops of teeth or roots, no broken teeth	missing fillings or caps, holes in teeth/roots	more than one missing fillings, caps or holes in teeth/roots	Changes or Unhealthy = see dental professional
Dentures or Partials	no broken areas or teeth, dentures worn regularly	broken or sharp area on tooth or dentures, only worn for one-two hours a day	more than 1 broken area/tooth, denture missing or not worn, or has need for denture adhesive	Changes or Unhealthy = see dental professional
Oral Cleanliness	clean and no food particles or buildup in the mouth or on dentures	food particles/soft or hard buildup in areas of the mouth or on denture	food particles/soft or hard buildup in most areas of the mouth or on most of the dentures	Changes or Unhealthy = see dental professional
Dental Pain	no signs of pain or mouth sensitivities	signs of pain like holding face, not eating, irritable or aggressive	signs of swelling, pimple on gum, broken teeth, large ulcers, holding face, chewing lips, not eating, irritable or aggressive	Changes or Unhealthy = see dental professional

Healthy mouths can be maintained with regular oral hygiene care (brushing, cleaning in between teeth, fluoride toothpaste or rinse), regular professional care (interval determined by the dental health professional) and yearly oral cancer exams.

From: Senior Oral Health, funded by United Way of Tucson and Southern Arizona and the Alliance of the ADA, c2005

Section 10

End-of-Life Issues

Starting the Conversation About End-Of-Life Wishes

You can help the person you care for, and yourself, by initiating a conversation about his or her wishes regarding end-of-life care. Although it is often difficult to speak honestly and openly about death and dying, it can be even more uncomfortable to have to make end-of-life decisions concerning a loved one without having had such a discussion. The majority of people who die from an illness, as opposed to a car accident or some other sudden means of death, will go through a period of days or weeks when they move in and out of consciousness and are unable to talk. This is why it is important to talk, while you still can, about the person's wishes for life sustaining treatment.

Barriers to Talking

Most families find that bringing up the topic is the hardest part. Once everyone gets past the initial discomfort, many find themselves relieved to have the issues out into the open. If the time does come when the person who is being cared for can no longer speak for him/herself, family members who know their loved one's wishes are spared the guilt and anxiety of trying to make difficult life-support decisions without previous guidance. As a potential decision maker, you may find it is in your best interest to start the quality of life conversation and encourage the person you care for to write down his or her wishes in an advance directive.

While 80% of Americans say they wish to die at home, only 20% do. And although 75% of Americans say they are in favor of advance directives, only 30-35% of them actually write one. The biggest barrier is procrastination-not getting around to it. In an ideal world, every adult would have an advance directive, no matter his or her age. Sudden accidents or illnesses occur all too frequently and often take us off guard. Within the context of a serious illness, there may be no time to put this decision off. If you need help in thinking about or discussing these issues, contact the Community Partnership for End of Life Care (a program of Hospice & Palliative CareCenter) or call 336-768-6157, ext. 622.

Conversation Starters

The American Bar Association tool kit is an excellent and very accessible resource to help patients and their families discuss matters concerning end of life care. The kit's articles address topics such as weighing the odds of survival, your personal priorities and spiritual values, how to select a health care representative, and how to be a health care representative.

There probably is no right time or right way to start a discussion about dying. Unless there is a story in the news that provides a good opening, you may want to begin with an indirect reference. For instance, you can talk about a friend who had problems when her parent died because the parent had not spoken with family members or written an advance directive. By expressing the personal distress you would feel if you were in that situation, you then can shift to asking the person you care for what he or she would like to have done "just in case." Many people who are sick care very deeply about not causing their family members pain or anguish. Once they realize that not talking about the situation will make it harder on the ones they love, they often can get past their resistance. Some are even relieved because they had wanted to talk about it but didn't know how to bring up the subject!

Sometimes it helps to open the conversation by acknowledging how awkward you feel: "I have something on my mind that is really uncomfortable to talk about, but I feel we need to. I wouldn't be a good [son/daughter/wife] if I didn't find out about your wishes for care if you get to the point at which you can't express them yourself."

Alternatively, if you know that the person you care for is very particular about how things are done, you might want to start the conversation by emphasizing his or her ability to remain in control, even at the end, through an advance directive. People with a serious illness often feel powerless about their disease and their situation. By planning ahead for their care, they will at least be able to direct those things that are still within their power to control.

Some people say their attorney advised them to have the conversation: "My attorney was talking to me about my need for an advance directive, and I realized I don't know much about you and your wishes." Others might start the conversation by noting something about famous people. For instance, "Neither Richard Nixon nor Jackie Kennedy was on life support when they died. I wonder if they had an advance directive."

You may want to look at a guide called *Isn't It Time We Talk*. It outlines several basic concepts you may want to cover in your discussion. In addition, this guide can be used to help the person you care for identify what it is he or she wants and values before going on to complete an official advance directive form. Our article about quality of life is also helpful in this regard. For factual information about commonly used life-support measures (e.g., the effectiveness and experience of CPR, tube feeding, the use of antibiotics, etc.), go to www.hospicecarecenter.org.

When Family Members Disagree

The person who is ill may have very clear thoughts about what he or she wants in terms of care at the end of life, but family members may not agree. This situation can make things very difficult for the professionals involved. They are legally and ethically bound to follow the patient's wishes. If all the paperwork is complete and available, then there is no question about what will be done.

Professionals recommend that you keep several copies and distribute them liberally so they are not difficult to find when they are needed. For instance, a safe deposit box is OK, but your doctor and lawyer should have copies, as should your health representative and your local hospital. Some even suggest keeping a copy in the glove compartment of your car and at home in your desk. If the person you care for is homebound, you may want to keep a copy in a drawer by the bedside so it is readily available for emergency medical personnel in case there is a call to 911.

To facilitate access to the advance directive, in many states you may have it registered electronically. This enables hospitals and health providers from around the country to have access to your advance directive 24 hours a day, 7 days a week. Check with your state attorney general; in some states a fee is involved, while other states are now offering this service for free.

With all the paperwork in place, your care receiver will have his or her wishes honored. However, that does not mean the situation will be a comfortable one if there is disagreement within the family. If a relative has strong feelings that are contrary to the wishes of the patient (whichever direction they lean), you would do well to resolve the conflict as soon as possible. Bringing in a professional such as a counselor, social worker, chaplain, or other spiritual advisor can help immeasurably. These professionals can help the patient express his or her feelings about quality of life in a safe environment. They can also provide opportunities for the dissenting family members to not only be heard, but also be guided to an understanding and acceptance of the patient's decision. Time and resources spent gaining family consensus before the death will be a good investment for helping everyone constructively process events after their loved one has died.

Responding to Resistance

Here are a few of the ways people often respond when someone brings up the subject of advance directives and end of life decisions:

"It'll be okay. I'll beat this thing. We don't need to discuss life support."
Denial is one of many ways we cope with problems that seem overwhelming. Although it is frustrating for family members, it can be a very important strategy for the person who is confronting mortality. However, it doesn't relieve you of the need to have the conversation. Rather than force the person you care about to accept the terminal nature of the disease, you can frame your need for a conversation in the context of "just in case." In a gesture of unity, you could also decide to make an advance directive yourself and suggest that the two of you do it together. This helps prevent the person who is ill from feeling marginalized and set apart. As a side benefit, it can provide you with an advance directive. People with terminal illnesses are not the only ones who need such a document. Accidents happen all the time, and those who may have to care for you would likely appreciate having a directive to help them make decisions on your behalf.

"It's all in God's hands."
Those who are religious or have strong life philosophies believe the moment of death is out of our control. Whether or not you agree with these beliefs, you can affirm your loved one's conviction and still point out that "a Higher Power has given us the responsibility to determine how we live up until death." You can communicate your need to know more about the person's wishes in case he or she is unable to describe those wishes when they are needed.

"It's too painful to talk about. Besides, talking about it is bad luck. It will only make it happen."
Rather than challenge your care receiver's beliefs about a premature demise, focus instead on the pain it will cause you if you don't have the discussion. You can first acknowledge his or her pain and discomfort with the subject. You can then share that you too, are in anguish at the prospect of making tough decisions and living with the guilt of making a decision that is different than what he or she would have wanted. You can also acknowledge discomfort by not insisting on an immediate conversation. Instead you can ask to set up a specific time in the next few days when the two of you can get together and talk. Sometimes spending a little time with the idea can make it easier to address later.

"There's no need to talk. You know me. I don't want any heroics."
Although this is a simple, straightforward response, unfortunately end-of-life decisions are not always about heroic measures. For instance, from what this person has said, one could reasonably assume that he or she would not want cardiopulmonary resuscitation (CPR), but what about antibiotics in the case of an infection with pneumonia? Or what about tube feeding if he was no longer taking in food or water? Our article about planning for healthcare decisions includes information about the medical and quality-of-life considerations that typically must be faced for each of the life-support measures.

Source: Hospice & Palliative Care Center, 2002-2014, www.hospicecarecenter.org

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National Center on Caregiving

Advanced Illness: Holding On and Letting Go

Introduction

Our culture tells us that we should fight hard against age, illness and death: "Do not go gentle into that good night," Dylan Thomas wrote. And holding on to life, to our loved ones, is indeed a basic human instinct. However, as an illness advances, "raging against the dying of the light" often begins to cause undue suffering, and "letting go" may instead feel like the next stage.

This fact sheet discusses the normal shifting emotions and considerations involved in holding on and letting go. Exploring these issues ahead of time will allow a person with a chronic illness to have some choice or control over his or her care, help families with the process of making difficult decisions, and may make this profound transition a little easier for everyone concerned.

The opinions of the dying person are important, and it is often impossible to know what those beliefs are unless we discuss the issues ahead of time. In caring for someone with memory loss, it is important to have the conversations as soon as possible, while he/she is still able to have an informed opinion and share it. Planning ahead gives the caregiver and loved ones choices in care and is most considerate to the person who will have to make decisions.

This fact sheet presents principal concerns, then discusses planning ahead, and some of the related matters that come up during chronic illness. Finally, it presents ideas on how to go about making the decisions when the time comes. All along the way, there are few, if any, right or wrong choices. This is a time to seek the answers that most respect the person experiencing advanced stages of an illness.

Holding On

Humans have an instinctive desire to go on living. We experience this as desires for food, activity, learning, etc. We feel attachments to loved ones, such as family members and friends, and even to pets, and we do not want to leave them. We do not so much decide to go on living, as find ourselves doing it automatically. Robert Frost said, "In three words I can sum up everything I have learned about life: It goes on." Even in difficult times, it is our nature to hold on for better times.

When we realize that the end of life may be approaching, other thoughts and feelings arise. The person who is ill will want to be with loved ones, and may also feel a sense of responsibility towards them, not wanting to fail them nor cause them grief. He/she may have unfinished business. For example, the person may or may not want to reconcile with estranged family members or friends. Fears arise, and may be so strong that they are hard to think about or even admit to: fear of change, of the dying process, of what happens after death, of losing control, of dependency and more. Both the person who is ill and the caregiver might also experience resentment, guilt, sadness and anger at having to do what neither wants to do, namely face death and dying.

Even in facing death, hope remains. The object of hope may change. As death comes closer, the family may hope for a restful night, or another visit with a particular friend, or just a quiet passing from this life to whatever we hope follows it. Often, as an illness progresses to an advanced stage, two seemingly incompatible ideas may arise in our minds. The Jewish prayer of the gravely ill puts it well for both the person who is ill and the loved ones caring for him/her: "I do not choose to die. May it come to pass that I may be healed. But if death is my fate, then I accept it with dignity."

Letting Go

As death nears, many people feel a lessening of their desire to live longer. This is different from depression or thoughts of suicide. Instead, they sense it is time to let go. Perhaps, as in other times in life, it's a sense that it's time for a major change like one might feel when moving away from home, getting married, divorcing or changing to a new job. Some people describe a profound tiredness, a tiredness that no longer goes away with rest. Others may reach a point where they feel they have struggled as much as they have been called upon to do and will struggle no more. Refusing to let go can prolong dying, but it cannot prevent it. Dying, thus prolonged, can become more a time of suffering than of living.

Family members and friends who love the dying person may experience a similar change. At first, one may adjust to managing a chronic illness, then learn to accept a life limiting illness, and then accept the possibility of a loved one dying. Some may refuse to accept the inevitability of death. Lastly, one may see that dying is the better of two choices, and be ready to give the loved one permission to die. As mentioned, the dying may be distressed at causing grief for those who love them, and, receiving permission to die can relieve their distress. There is a time for this to happen. Before that, it feels wrong to accept a loss, but after that it can be an act of great kindness to say, "You may go when you feel it is time. I will be okay."

Other Concerns

Letting go gets mixed up in our minds with a person wanting to die, although these are really separate situations. There are various reasons a person may want to die, reasons quite separate from those for letting go. Depression is one response to finding life too painful in some way. Some people cannot tolerate losing control, so they want to take control of dying. It can be unpleasant to be disabled, or in a place one does not want to be, or isolated from the important people and things in one's life. Very often, a severely ill person feels like a burden to family and friends, and may wish to die rather than let this continue. Fears of the future, even of dying, may be so great that a person wants to die to get away from that fear. Inadequately controlled pain or other symptoms can make life seem unbearable.

For many of these situations the right sort of help can make a great improvement, and replace the desire to die with a willingness to live out this last part of one's life. At this time, professionals such as mental health providers, a hospice team evaluation, or pain-management specialist, may be called upon for consultation.

Chronic Illness

So far, this fact sheet has been about the very end of life. Many, or even most, people go through a period of chronic illness before they die. Along the way there are numerous choices to make. Caregivers and people they care for have to decide whether or not to get a particular treatment or procedure. How long can one keep trying to do usual activities, including work, and when does it seem time for one to face that that phase of life is over? Most of us have things we have dreamed of doing, but never got around to. Now may be the time to do that thing, no matter how difficult, or it may be time to let it be just a beautiful dream. Chronic illness brings up one situation after another where caregivers and care receivers must do their best to communicate about beliefs and options, and then decide either to hold on or to let go.

Planning Ahead

Planning ahead means thinking about what is important, and what is not. It also means talking about this with those close to us. Even though we think we know what someone else thinks and believes, we really do not know until we ask. You cannot read other people's minds.

When we think about the last part of our own or someone else's life, consider these questions:

- What makes life worth living?
- What would make life definitely not worth living?
- What might at first seem like too much to put up with, but then might seem manageable after getting used to the situation and learning how to deal with it?
- If I knew life was coming to an end, what would be comforting and make dying feel safe?
- What, in that situation, would I most want to avoid?

Knowing what really matters to you is worth considering. How important is being able to talk with people, engaging in daily activities, physical comfort or general alertness to you? What comes to mind when you think about the burden of care on others, being at home, or not being there? How much distress is it worth in order to live another month? And what medical procedures are not worth enduring? From your perspective, what is the best way for a person to die, and how important is it to you to be in control of how you live and how you die? Whose opinion should be sought in making choices about the care received when an illness has progressed to an advanced stage?

One especially important matter is to complete the Advance Health Care Directive for both the person who is ill and the caregiver, so that there is an official spokesperson when one is too sick or too confused to speak for him/herself.

If, as caregivers, we haven't had the necessary conversations—whether due to reluctance, dementia, or a crisis—we might have to think about the issues raised above without a lot of information.

Some questions that might help in thinking about this are:

- What has that person actually told me?
- How can I find out for sure about her or his wishes?
- Turning now to myself as the caregiver, what would be important to me?
- What would I especially like to know about that person's wishes?
- What would be the limits of what I could do?
- Could I take time off work? How much? What are my financial constraints?
- What physical limitations do I have?
- What kinds of care would be just too much emotionally for me?

- Might I provide more comfort if I let go of some of the daily hands-on caregiving, and allow someone else, even a paid caregiver, to assume this role?
- Am I willing to accept the responsibility of being someone's official spokesperson?
- If that person has relatives who would be especially difficult to deal with, how would I manage being the official maker of decisions?

All of these questions may sound very difficult to discuss now, when the time for decisions is still in the future. However, they are harder to discuss when someone is really sick, emotions are high, and decisions must be made quickly. Chronic pain, frailty, and cognitive decline may take away the ability to discuss complicated issues. The earlier everyone sits down to talk, the better. The best way to start is simply to start. Arrange a time to talk. You may say you want to talk about things that might happen in the future, in case of serious illness. Have some ideas to bring up. Be prepared to listen a lot, and to ask questions. Do your best not to criticize what the other person says. If you know the other person will not want to talk much about this topic, have just one or two important things to say or to ask about. Be prepared to break off the conversation, and to come back to it another time. Write down the important things people say. Eventually, you can use your notes to prepare a statement of wishes and make this statement part of an "advance directive" about health care decisions, whether or not the formal document has been completed.

Many families find it is easier to have such a critical discussion with the presence and guidance of an impartial facilitator. Some social workers, case managers, or faith-leaders are skilled in providing this support (see added resources). Asking for a professional to assist with the discussion may relieve individual family members from the burden of having to take on this role.

It is also important to talk with your physician about treatment choices. You may ask the doctor to complete a POLST, or Physician's Orders for Life Sustaining Treatment. (Visit www.polst.org to find out if your state offers a POLST program, or in states without POLST, ask the doctor about a DNR order - Do Not Resuscitate). This form is a set of medical orders, similar to the DNR (allow natural death to occur). On this form one can state that he/she does or does not want to be resuscitated, and whether or not one would want a feeding tube, ventilator and other treatments. Decisions to provide or withhold life support are based on personal values, beliefs and consideration for what a person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt, guilt or blame that may surface.

POLST is not for everyone. Only individuals with serious, progressive, chronic illnesses should have a POLST form. For these patients, their current health status indicates the need for standing medical orders. For healthy individuals, an Advance Directive is an appropriate tool for making future end-of-life care wishes known to loved ones. Professionals in medical offices, hospitals, community-based services, and hospice teams are skilled at assisting individuals or family groups at working with these very normal, but painful, emotions.

Making the Decision

Is it time to let go? Or time to give a loved one permission to die? There are three ways to help decide.

First, look at the medical situation. Has the illness really reached its final stages? When it has, the body is usually moving on its own toward dying, with strength declining, appetite poor, and often the mind becoming sleepier and more confused. Treatments are no longer working as well as before, and everyday activities are becoming more and more burdensome. In a sense, life is disappearing. Consult with your physician; ask for clarity on the prognosis, or likely course of the illness or stages of dying.

Closer to death, there may be dramatic changes in the dying person's moods, behaviors, desire to take food or water, and capacity to verbalize wishes. All of this may be a normal part of his or her letting go. At this time, safety and comfort care are of utmost concern.

Second, talk with people you trust. Discuss the situation with the family members and friends who seem to be able to see things as they are. You might also talk with people who are not personally involved. Most importantly, consider what the dying person has expressed or you know to be his or her desires.

Third, listen to your heart. Try to see beyond your fears and wishes, to what love and caring are saying to you. What is really best for the one who is dying, and for the others around? Given that death is unavoidable, what is the kindest thing to do? It might be holding on. It might be letting go.

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Source: Prepared by Family Caregiver Alliance. Reviewed by Beth MacLeod, LCSW, Care Consultations and Therapy, San Francisco, CA. Funding provided by the Stavros Niarchos Foundation.

Palliative Care Frequently Asked Questions

What is palliative care?
Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

How do I know if palliative care is right for me?
Palliative care may be right for you if you are experiencing pain, stress and other symptoms due to a serious illness. Serious illnesses include but are not limited to: cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, AIDS, amyotrophic lateral sclerosis (ALS) and multiple sclerosis. Palliative care is appropriate at any stage of a serious illness and you can get it along with treatment meant to cure you.

What does palliative care do?

- Pain and symptom control: Your palliative care team will identify your sources of pain and discomfort. These may include problems with breathing, fatigue, depression, insomnia, or bowel or bladder. Then the team will provide treatments that can offer relief. These might include medication, along with massage therapy or relaxation techniques.
- Communication and coordination: Palliative care teams are extremely good communicators. They put great importance on communication between you, your family and your doctors in order to ensure that your needs are fully met. These include establishing goals for your care, help with decision-making and coordination of care.
- Emotional support: Palliative care focuses on the entire person, not just the illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have.
- Family/caregiver support: Caregivers bear a great deal of stress too, so the palliative care team supports them as well. This focused attention helps ease some of the strain and can help you with your decision making.

What can I expect?
You can expect to have more control over your care and a comfortable and supportive atmosphere that reduces anxiety and stress. Your plan of care is reviewed each day by the palliative care team and discussed with you to make sure your needs and wishes are being met and that your treatments are in line with your goals. You can also expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care addresses the whole person. It helps you carry on with your daily life. It improves your ability to go through medical treatments. And it helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.

Will my insurance cover palliative care?
Most insurance plans cover all or part of the palliative care treatment you receive, just as with other hospital and medical services. This is also true of Medicare and Medicaid. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.

Do I have to give up my own doctor?
The palliative care team provides an extra layer of support and works in partnership with your primary doctor. Your primary doctor will continue to direct your care and play an active role in your treatment.

Can I have curative treatment together with palliative care?
Absolutely. Your treatment choices are up to you. You can get palliative care at the same time as treatment meant to cure you.

Who else, besides the patient, can benefit?
Everyone involved! Patients as well as family caregivers are the special focus of palliative care. Your doctors and nurses benefit too, because they know they are meeting your needs by providing care and treatment that reduces your suffering and improves your quality of life.

Where do I get palliative care?
Palliative care can be available in a number of places. These include hospitals, outpatient clinics, long-term-care facilities, hospices or home.

Who provides palliative care?
Usually a team of specialists, including palliative care doctors, nurses and social workers, provide this type of care. Massage therapists, pharmacists, nutritionists and others might also be part of the team. Generally, each hospital has its own type of team.

Can I get palliative care if I am at home?
After discharge from the hospital, you, your doctor and the palliative care team can discuss outpatient palliative care. Some hospitals also offer outpatient palliative care even if you have not been in the hospital. Check with your doctor.

What is the difference between hospice and palliative care?
Palliative care is for anyone with a serious illness. You can have it at any age and any stage of an illness, and you can have it along with curative treatment. It is not dependent on prognosis. Hospice is an important Medicare benefit that provides palliative care for terminally ill patients who may have only months to live. People who receive hospice are also no longer receiving curative treatment for their underlying disease.

How do I get palliative care?
Ask for it! Start by talking with your doctor or nurse.

Source: www.GetPalliativeCare.org

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Advocacy, Action, Assistance

Hospice FAQs

Helping older relatives or friends make more informed choices about end of life decisions.

Frequently Asked Questions about Hospice

At the end of a life limiting illness, there may come a time when a person chooses to stop receiving aggressive treatment efforts. In your role as a caregiver, this may be an appropriate time to discuss the option of hospice care with your loved one.

What is Hospice and Palliative Care?
The hospice approach to care focuses on comfort and dignity for the dying patient and the patient's family. The focus is on caring, not curing. This approach is called palliative care and aims for pain relief and symptom control rather than cure.

Hospice services are provided by a team of physicians, nurses, social workers, counselors, certified nursing assistants, clergy, and volunteers. Hospice care is available to anyone with a terminal illness who is expected to pass away within six months if the illness follows its normal course. Unfortunately, many patients receive hospice services for only their last few weeks of life when they actually could have benefitted from hospice services for several months.

The basic principles of hospice care are:

- **Death with dignity.** Provide end-of-life care that eases both physical and emotional pain.
- **Palliative care.** Help the patient experience quality of life through relief of suffering and control of symptoms.
- **Individual control over life.** Involve the patient in all aspects of care and respect the choices the patient makes.
- **Ongoing support for the patient, family and friends.** Ensure the patient and the patient's family feel understood, reassured, and validated during this difficult time.
- **Importance of family.** Family and friends are fundamental to the well-being of the patient and should be as involved as the patient would like them to be.

Does hospice provide any services for the family of the dying patient?
Hospice understands that those who are close to a dying person experience the dual pains of shared suffering and anticipated loss. Hospice provides continuing support for caregivers for at least one year following the death of a loved one and sponsors bereavement groups and grief support groups.

What kind of services does hospice provide?
Hospice provides medical and nursing care, medical equipment and supplies, medication therapy for pain and symptom control, homemaker services, social work services, counseling, respite care, religious support and the coordination of all services needed by the patient and family. Respect for the individual's ethnicity, cultural beliefs, and sexual orientation are reflected in the services and program of hospice care.

PASSAGES
Support and Education in End of Life Issues

Dispelling Myths About Hospice

Myth – Hospice is just a place to send people when they are dying.
Hospice is not a place, but a way of caring for people add their families who are facing their final six months or so of life. Hospice helps them remain as comfortable, functional and dignified as possible, providing physical, emotional and spiritual support. With the support of the hospice team, most people are able to remain in their own homes, surrounded by the people and things they love.

Myth – Choosing hospice is giving up
Hospice affirms life and helps people live as fully and comfortably as possible when cure is no longer possible. It is a way to realistically and humanely manage the final stage of life and an opportunity to redefine and experience hope and healing.

Myth – Hospice is only for those who are near death
Hospice accepts those people who are in their final six months of life, allowing time for support, education, to allay fears and live fully the remainder of their days.

Myth – Once hospice is chosen, the person is no longer in control of their care.
The terminally ill person and their family remain in control of their care. The job of hospice is to support them in a way that respects their value and goals. The person always has the right to change their mind about the selection of hospice care, the provider of hospice care, and may choose to cancel hospice at any time should they again seek aggressive curative treatment.

Myth – Hospice is the same as euthanasia
Hospice neither hastens death nor prolongs dying. The honor both life and the natural process of dying, assuring as much comfort and function as possible within the limits of the disease.

Myth – Hospice care is expensive
Under Medicare and most insurance companies, hospice care is **covered 100%,** relieving families of many financial burdens. Covered services include nursing visits, social workers, bereavement counselors, spiritual counselors, home health aides, volunteers, physical and speech therapy, all working under the direction of your physician. Medication and equipment and many personal supplies necessary for the comfort and safety are also covered and delivered to your home, as well as short-term inpatient stays for symptom management or respite. No one is refused because of their inability to pay.

Hospice frequent visits, comprehensive support and 24-hour availability helps the person avoid costly and unnecessary hospitalization and trips to the ER.

Myth – Hospice is just for people who have cancer
Hospice cares for anyone facing a terminal disease or natural end of their lives. This includes old age, dementia, heart and lung disease, neurological disorders, and more.

Myth – Hospice stops all medications and treatments
Hospice is very aggressive in providing excellent comfort care. This includes medication, oxygen and other treatments necessary the enhance quality of life. They will work with your physician to determine the best possible plan of care to assure your comfort.

Myth – Hospice is depressing
While it is always sad to realize someone you care about is facing the end of their life, hospice helps that person and family discover ways to create meaning, find healing, share stories and leave a legacy and make the most of the days and months that remain. This is life affirming and can be as filled with laughter as it can with tears. Hospice is a guide for the journey to lessen fear and promote communication and quality of life.

Did you know this about hospice?

- Services are available 24 hours a day, 7 days a week with intermittent visits by the hospice team.
- You doctor remains in charge of your care unless you choose otherwise or if he or she feels you will get the best care with a physician who specializes in comfort care.
- The majority of people are able to remain in their own homes until death.
- Two studies show that people actually live longer under hospice care due to good symptom control and decreased aggressive treatment that may occasionally hasten the end of life.
- A number of people improve so much under the hospice teams ability to manage symptoms that they are discharged because the doctor feels they are no longer in a terminal phase (the last six months)
- Your right to choose never ends. You can:
  - ➢ Decide to try curative treatment again and sign out of hospice. If you get better, we are thrilled for you. If treatment fails, the person are welcomed back to resume hospice support and care.
  - ➢ Change hospice programs if one isn't meeting your needs
- No one has a crystal ball. A six month prognosis is our best educated guess based on your disease. Hospice will continue to provide care after 6 months as long as your health status and goals still meet criteria for care.

FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

Advanced Illnesses: CPR & DNR

Introduction

Big issues - and big decisions - confront us when we think about the imminent death of a terminally ill loved one in our care. Among the emotional, legal and financial considerations are also questions regarding the type of medical assistance your loved one should receive as their illness advances. For example, if your loved one suddenly has difficulty breathing, will you allow a paramedic or an emergency room technician to administer CPR? And if CPR revives your loved one, yet he or she still can no longer breathe on his or her own, should you allow a machine - a respirator - to breathe for him or her?
A better understanding of cardiopulmonary resuscitation, or CPR, can be helpful when it comes to making this difficult choice before a crisis occurs. This Fact Sheet specifically addresses the process of CPR and describes the DNR (Do Not Resuscitate) form, the legal document used to indicate to medical professionals your - or your loved one's - wishes. (For a more detailed discussion of the other issues involved in planning for the end of life, see the Family Caregiver Alliance fact sheets, End-of-Life Care Planning: Decision Making, and Advanced Care: Feeding Tubes and Ventilators).

CPR (Cardiopulmonary Resuscitation)

Consider the following scenario:
Nancy's husband has had Alzheimer's disease for eight years, and is now in the final stages of the illness. After a discussion of end-of-life issues with her family, Nancy has decided to "let nature take its course" if anything of an urgent medical nature happens to her husband. In other words, she does not want him to be put on life support. She has told her doctor of this decision, and he has concurred.

One night, Nancy wakes up to find her husband having trouble breathing. Reflexively, without thinking, she calls 911. By the time the paramedics arrive, her husband has stopped breathing completely. The paramedics leap to do their job: they immediately administer CPR and take him to the hospital. By the time Nancy arrives at the hospital, her husband is connected to a ventilator and numerous IVs. Unfortunately, this is exactly what she did not want for him.

Definition

Fully understanding Nancy's scenario requires a deeper understanding of cardiopulmonary resuscitation. Simply put, CPR is the process of restarting the heartbeat and breathing after one or both has stopped. The first step involves creating an artificial heartbeat by pushing on the chest, and attempting to restore breathing by blowing into the person's mouth. A medical professional will then insert a tube through the mouth and down the airway to make the artificial breathing more efficient. Electric shocks may be given to the heart, and various drugs may be given through an intravenous line. If the heartbeat starts again but breathing is still not adequate, a machine called a ventilator may be employed to move air in and out of the person's lungs indefinitely.

On television, CPR is often depicted as the ultimate life-saving technique. However, television does not show this process quite accurately - in real life the process is more brutal. Pushing the center of the chest down about one and one-half inches, 100 times a minute for several minutes, causes pain, and may even break ribs, damage the liver, or create other significant problems. CPR produces a barely adequate heartbeat, and doing it more gently is not sufficient to circulate enough blood. Electric shocks and a tube in the throat are also harsh treatments, but may be essential to resuscitate someone.

CPR frequently can save a person's life, particularly in the case of some kinds of heart attacks and accidents an otherwise healthy person may experience. CPR is also most successful when the failure of heartbeat and breathing occurs in the hospital, in the Cardiac Care Unit (CCU). Nurses in the unit will instantly recognize the problem and begin sophisticated care.

However, when a person is in failing health from a serious and progressive illness, the heart and breathing will ultimately fail as a result of that illness. In such a circumstance, there is little chance that CPR will succeed at all. Any success will be temporary at best, because the person's weakened condition will soon cause the heartbeat and breathing to fail again.

Another possibility is that CPR may be only partially successful. If the heartbeat is restored but a person is still too weak to breathe on his or her own and remains too weak to do so, he or she may be on a ventilator for days, weeks, months or longer. Moreover, when breathing or heartbeat fails, the brain is rapidly deprived of oxygen. As a result, within seconds, the brain begins to fail (one loses consciousness), and within a very few minutes permanent damage to the brain occurs. If it takes more than those very few minutes to start effective CPR, the person will not fully recover. The brain damage may mean anything from some mental slowing and loss of memory to complete and permanent unconsciousness and dependency on a ventilator and sophisticated medical life support.

The Role of Emergency Help (Calling 911)

A call to 911 is a request for emergency help; the goal of those who respond to 911 calls is to protect life and property, and the people who respond expect to go to work doing what they are trained to do to accomplish that goal. If your house is on fire, the firefighters don't ask for permission to cut a hole in your roof and spray water all over your living room - they just do what is necessary to stop the fire from destroying your home.

Similarly, when a person's heartbeat and breathing have failed, the 911 responders are not prepared to have a long talk with you about the person's condition and what you think might be best to do. They know that any delay could mean brain damage, so they immediately start CPR and then take the person to the hospital. With one exception, which we will discuss in the next section, their rules require this, and it makes sense if you think about the purpose of the 911 system.

When Nancy called 911 in our scenario, the paramedics simply did what they are trained to do - they revived her husband. However, if Nancy and her doctor had completed a DNR form and kept it in the home, her husband would not have been resuscitated and/or connected to machines when he got to the hospital.

The Do Not Resuscitate (DNR) Form

The Emergency Medical Systems Prehospital Do Not Resuscitate (DNR) Form is a legal document that gives the 911 responders permission not to perform CPR. The DNR form is prepared in advance of any situation and kept at home. This prehospital DNR form lists the name of the person to whom it applies, and is signed by that person (or whoever represents that person if he or she is too ill to make medical decisions on his or her own behalf). It is also signed by the person's doctor. Please note this is very important: the form is not valid until the doctor signs it, as it is a medical order. There is a new form which can replace or be a supplement to the traditional DNR order called a POLST (Physician Orders for Life Sustaining Treatment). See Fact Sheet: Advanced Medical Directives for more information on POLST.

The DNR or POLST is the only form that affects 911 responders; other documents, such as a Durable Power of Attorney for Health Care or some other Advanced Directives, do not. If emergency personnel arrive to find a person whose heartbeat and breathing have failed or are failing, they will perform CPR unless they see a correctly completed DNR/POLST.

In light of this, the DNR/POLST form should be kept near the ill person's bed, perhaps on the wall, so it will be easy to find in case of emergency. When 911 responders see this form, they will still do anything they can to make the sick person comfortable, but they will not perform CPR. In the absence of a DNR/POLST form, they must do CPR. The DNR/POLST is the only form that gives you control over what they may do. (Note: A DNR may be reversed if you so desire.)

Choices

Why would one choose to prepare a DNR? Because, as we've discussed above, there are times when it may not make sense to perform CPR. As an illness progresses, there usually comes a time when continued treatment will no longer reduce symptoms nor heal the person and he/she is in an end stage of the disease. (When a person is becoming more and more sick, doctors may try various treatments to stop the illness, but eventually it may become clear that treatments are not having the desired effect. Other treatments might provide comfort, and might even partly control the disease, but a point may be reached where nothing will stop the person's decline.) Under these circumstances, you might feel there is little reason to attempt CPR, as it (At this point, CPR) may only prolong dying. This allows natural death to occur. In fact, the original name of the DNR form was "DNAR" for "Do Not Attempt Resuscitation." This name recognized the fact that the form instructed the 911 responders not to undertake something that, despite the best efforts, would not work effectively in the long run. At most, the effort might put the sick person in the hospital, in pain and distress, for the last days of his or her life. Having a DNR prepared may also relieve the caregiver of making a decision to turn off a machine, which can be an even more difficult decision psychologically.

(See the FCA fact sheets, End-of-Life Choices: Holding On and Letting Go and End-of-Life Decision Making for more discussions about this issue).

Conclusion

When someone is suffering from a chronic illness, as opposed to an acute illness (the kind that usually requires a hospital visit or stay), the decline is often gradual. As a result, both caregivers and those in their care often forget to talk about the choices the chronically ill person would like to make regarding his or her health care. If you decide that you do not want CPR and are concerned about this decision, it might help to talk with your physician and clergyperson. It is normal, instinctive, to try to save life no matter what, and some people are concerned that not doing everything possible to preserve life is the same as “killing” someone. But it can also simply mean respecting the end stage of a disease as the body shuts down and death naturally occurs.

There are no right and wrong answers to these questions, and until we face a situation like this, it is difficult to anticipate the kinds of choices we’d make. As we change throughout the course of an illness, our choices might also change. However, the more thoroughly family members have discussed these issues in advance of the need to make a critical decision, the easier it will be on both the person who is ill and those responsible for that person’s care. It is never too soon to start the conversation. Hospice care can relieve suffering and provide support to patients and families facing these crises.

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Death at Home

Helping older relatives or friends make more informed choices about end of life decisions.

Reaching the end of your caregiver journey can be a very emotional time that demands courage and compassion. You may want to "be there" for your relative, providing support and making sure his or her wishes are carried out. Often, we foresee the death of our family member as we witness gradual declines in his or her health and functioning, but sometimes death comes suddenly.

Frequently Asked Questions about a Death at Home

How do we begin to prepare for this time?

The first step in preparing for a death at home is to gather the facts.

- Learn about the disease or condition that affects your relative by talking with the health professionals providing care. Ask about symptoms, changes in health or behavior that may occur and the "normal" course of the disease and/or condition.
- Contact organizations or foundations that are likely to have information on what you can expect, such as the Alzheimer's Association, the American Heart Association, the American Cancer Society, the Parkinson's Association, etc.
- If your relative has a terminal illness, you may want to become familiar with the services and benefits offered by hospice care. The hospice approach to care focuses on comfort and dignity for the dying patient and his or her loved ones. All efforts are made to allow the person the comfort of dying at home. Your relative should feel free to discuss hospice care with his or her physician at any time.

My relative is seriously ill and I'm afraid if she dies I won't know what to do. Where can I turn for guidance?

It is frightening to face this situation without the resources you need. Having information and resources, as well as knowing your relative's preferences, will help you manage this difficult time.

If your relative does not want to receive CPR or other advanced life support efforts in the event his or her heart stops beating or breathing ceases, he or she can complete a "Prehospital Medical Care Directive" form, also known as an "orange form" because it must be printed on orange paper to have legal effect. These forms can be obtained from PCOA at (520) 790-7262.

Funeral Consumers Alliance has a wealth of information on getting one's affairs in order, what to expect when death occurs, and planning for burial or cremation. They can be reached at (520) 721-0230 or www.funerals.org. There are also several agencies that accept body and organ donations for research. Most of these agencies cover the costs of transportation and cremation of the body. Call PCOA for a list (520)790-7262.

Passages is a local Tucson agency that provides support and education in end-of-life issues. They can be reached at (520) 400-0274 or www.passageseducation.org.

What can you expect if your relative dies at home?

If your relative is enrolled in a hospice program, you will be instructed to call the hospice emergency number **instead** of 911. Hospice staff are highly trained professionals and will know exactly what to do. Staff will come to the home, assist with details and offer support.

If your relative is not in a hospice program it will be necessary to call 911 immediately to report the situation. After you have called 911 or the hospice team, **consider calling a friend or support person to come and stay with you while you wait.** When the 911 team responds, they will—as a matter of procedure—notify the Police or Sheriff's Department. The primary doctor of the deceased will be contacted to determine if the death is expected and to determine if the physician is willing to sign the death certificate. If the physician indicates that it is an expected event (such as with a terminal illness) then arrangements will be made to take the deceased person to the designated mortuary or funeral home.

If the cause of death is questionable, and/or your relative's doctor is unwilling to sign the death certificate, law enforcement will have the body transported to the medical examiner's office. The body of the deceased person will be released after the medical examiner determines the cause of death. This usually creates a delay of a few days or less, depending on the circumstances.

Is there always an autopsy?

No, the office of the medical examiner only conducts an investigation or autopsy if there is enough information to indicate a crime may have been committed. They are well trained in cultural and religious differences and make every effort to honor the beliefs of those who object to an autopsy. However when necessary, it is part of the procedure.

How long will the whole process take?

Depending on the circumstances, the process of removing the body can be very time consuming and may span several hours. Losing a loved one is very difficult even when anticipated, and perhaps more so if the death is sudden. It is important that you try to stay calm, and that you not disturb the situation until the 911 team and law enforcement arrives.

What kind of questions will be asked?

Primarily, responders will ask questions about your relative's past medical history, medications taken and for what conditions, treatments being administered, as well as the names and contact numbers of treating physicians. They may ask about your relative's overall well-being, how much assistance he or she needed to conduct daily activities and other routine questions to clarify the circumstances surrounding the death.

Resources

For a list of Grief Support Groups, contact:
Pima Council on Aging at (520) 790-7262 or TMC Hospice at (520) 324-2438.

Pathfinder: Death at Home FAQs - Revised 06/2014

FAMILY CAREGIVER ALLIANCE®
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Grief and Loss

Introduction

Grief is a natural process, an intense fundamental emotion, a universal experience which makes us human. It is a process that entails extremely hard work over a period of many painful months or years. People grieve because they are deprived of a loved one; the sense of loss is profound. The loss of a spouse, child or parent affects our very identities - the way we define ourselves as a husband, wife, parent or offspring. Moreover, grief can arise from the survivor's sudden change in circumstances after a death and the fear of not knowing what lies ahead.

The death of someone close can be a life-changing experience. If you are the primary caregiver of someone you love, this experience can affect every aspect of your life for some time. It is natural to grieve the death of a loved one before, during and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about.

Anticipatory Grief

If someone has had a prolonged illness or serious memory impairment, family members may begin grieving the loss of the person's "former self" long before the time of death. This is sometimes referred to as "anticipatory grief." Anticipating the loss, knowing what is coming, can be just as painful as losing a life. Family members may experience guilt or shame for "wishing it were over" or seeing their loved one as already "gone" intellectually. It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues and seek out the support of spiritual advisors, family and friends. And, depending on the impaired person's intellectual capacity, this can be a time to identify your loved one's wishes for burial and funeral arrangements.

Sudden Loss

A death that happens suddenly, unexpectedly, is an immeasurable tragedy. This type of loss often generates shock and confusion for loved ones left behind. Incidents such as a fatal accident, heart attack, or suicide can leave family members perplexed and searching for answers. In these cases, family members may be left with unresolved issues, such as feelings of guilt that can haunt and overwhelm a grieving person. These feelings may seem to take over your life at first. But over time it is possible to get past these thoughts and forgive yourself and your loved one. Give yourself plenty of time; it's virtually impossible to make yourself "move on" before you're ready. People experiencing the sudden loss of a loved one have a particular need for support to get through the initial devastating shock, pain and anger. Family members, close friends, and clergy can be vital lifelines for the griever.

How Long Does Grieving Last?

Grief impacts each individual differently. Recent research has shown that intense grieving lasts from three months to a year and many people continue experiencing profound grief for two years or more. Others' response to this extended grieving process may sometimes cause people to feel there is something wrong with them or they are behaving abnormally. This is not the case. The grieving process depends on the individual's belief system, religion, life experiences, and the type of loss suffered. Prolonged bereavement is not unusual. Many people find solace in seeking out other grievers or trusted friends. However, if feelings of being overwhelmed continue over time, professional support should be sought.

Symptoms of Grief

Grief can provoke both physical and emotional symptoms, as well as spiritual insights and turmoil.

Physical symptoms include low energy or exhaustion, headaches or upset stomach. Some people will sleep excessively, others may find they are pushing themselves to extremes at work. These activity changes may make an individual more prone to illness. It is important to take care of yourself during this period of bereavement by maintaining a proper diet, exercise and rest. Taking care of your body can help heal the rest of you, even if you do not feel inclined to do so.

Emotional symptoms include memory gaps, distraction or preoccupation, irritability, depression, euphoria, wailing rages and passive resignation. Some people identify strongly with the person who died and his/her feelings. If you have experienced a loss and are hurting it is reasonable that your responses may seem "unreasonable." Nonetheless, it is important not to judge yourself too harshly as you experience conflicting and overwhelming emotions.

Like grief itself, people's coping strategies vary. Some people cope best through quiet reflection, others seek exercise or other distractions. Some have a tendency to engage in reckless or self-destructive activities (e.g., excessive drinking). It is vital to obtain support in order to regain some sense of control and to work through your feelings. A trained counselor, support group, or trusted friend can help you sort through feelings such as anxiety, loss, anger, guilt, and sadness. If depression or anxiety persist, a doctor or psychiatrist may prescribe antidepressant drugs to help alleviate feelings of hopelessness.

Spirituality: you may feel closer to God and more open to religious experiences than ever before. Conversely, many people express anger or outrage at God. You may feel cut off from God or from your own soul altogether—a temporary paralysis of the spirit. If you are a person of faith, you may question your faith in God, in yourself, in others or in life. A member of the clergy or spiritual advisor can help you examine the feelings you are experiencing. Learning to deal with grief is learning to live again.

Stages of Grief

Often portrayed as a grief "wheel," these stages do not necessarily follow a set order. Some stages may be revisited many times as an individual goes through a grieving period:

- Shock
- Emotional release
- Depression, loneliness and a sense of isolation
- Physical symptoms of distress

- Feelings of panic
- A sense of guilt
- Anger or rage
- Inability to return to usual activities
- The gradual regaining of hope
- Acceptance as we adjust our lives to reality

Most people who have lost someone close go through all or some of these stages, although not necessarily in this specific order. This kind of healthy grieving can help a person move through a significant loss with minimal harm to self, either physical or mental.

Ethical Issues

Often family members and caregivers are faced with the decision to allow someone to die naturally or to prolong their death and maintain life through artificial means. Physician training, hospital and nursing home policies often dictate the use of "heroic means" to sustain life. "Reviving" a very ill person after a stroke or using a respirator for someone deemed medically "brain dead" are standard procedures used in many hospitals.

If at all possible, it is important to learn and document a person's wishes about using artificial life support before any crisis arises. A living will or durable power of attorney for health care (DPAHC) expresses a person's wishes when he or she can no longer speak for him/herself. These documents can help instruct hospitals or nursing homes on an appropriate course of action to be taken at a critical moment. By law, all hospitals must now inform patients about their right to fill out these documents.

When a person is confused, or otherwise unable to express preferences, family members are often put in the position of becoming surrogate decision makers. Such decisions present a thorny array of medical, legal, and moral questions. Decisions to provide or withhold life support are based on personal values, beliefs, and consideration for what the person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt or blame which may surface.

Tips for Helping the Bereaved

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own. This can have the effect of dismissing the grieving person's pain.
- Allow the grieving person to use expressions of anger or bitterness, including such expressions against God. This may be normal behavior in an attempt to find meaning in what has happened.
- Realize that no one can replace or undo the loss. To heal, the individual must endure the grief process. Allow him/her to feel the pain.
- Be patient, kind and understanding without being patronizing. Don't claim to "know" what the other person is feeling.

- Don't force the individual to share feelings if he/she doesn't want to.
- Physical and emotional touch can bring great comfort to the bereaved. Don't hesitate to share a hug or handclasp when appropriate.
- Be there later, when friends and family have all gone back to their routines.
- Remember holidays, birthdays, and anniversaries which have important meaning for the bereaved. Offer support during this time. Don't be afraid of reminding the person of the loss; he/she is already thinking about it.

Practical Assistance for the Bereaved

Things a person can do without asking:

- Send a card or flowers.
- Bring food.
- Water or mow their lawn.
- Donate blood.
- Contribute to a cause which is meaningful to your friend or family member.

Things a person can do to help but should ask first:

- Offer to stay in the home to take phone calls, receive food and guests.
- Offer child care on a specific date.
- Offer to care for pets.
- Offer transportation.

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Source: Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health. Printed December 1996. © All rights reserved. www.caregiver.org/grief-and-loss

Section 11

Legal and Financial Issues

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Advocacy, Action, Assistance

Definitions of Legal Documents

Helping older relatives or friends ensure that their preferences regarding medical care and/or financial decisions will be followed in the event of incapacitation or inability to communicate.

All of the documents listed below are meant to be discussed and shared with family members and appropriate professionals. They should be stored in an easily accessible location and not locked in a safe deposit box or filing cabinet.

Advance Directives

This is a generic term for a group of documents that are prepared by a person in advance to ensure that, in the event he or she becomes incapacitated or unable to communicate, his or her wishes will be followed. In order to be legally valid, the person signing an advance directive must be able to understand the nature of the document being signed. An advance directive can be revoked.

Living Will

A Living Will allows a person to identify ahead of time which medical procedures or interventions he or she does or does not want to receive. It is intended to be used as a guide to treatment in the event that he or she becomes unable to make or communicate decisions due to an irreversible coma, persistent vegetative state, or similar type of condition. A Living Will may be a stand-alone document or included as part of a Health Care Power of Attorney (see below).
NOTE: When creating a Living Will, it is important to talk to a doctor about the meaning of all the terms and treatments that are included, as well as the potential implications of the decisions being made.

Durable Health Care Power of Attorney

A Durable Health Care Power of Attorney allows a person to choose another individual—an "agent"—to make health care decisions on his or her behalf in the event that he or she becomes too ill to make or communicate decisions. Once the person regains the ability to communicate or make decisions, the agent is no longer authorized to do so on his or her behalf. This document can include a person's wishes regarding the medical procedures or interventions that he or she does or does not want to receive.
NOTE: A Medical or Health Care Power of Attorney gives the agent authority to make all medical care decisions unless specific limitations are included ahead of time.

Pre-Hospital Medical Care Directive

Pre-Hospital Medical Care Directives are sometimes called Do Not Resuscitate forms or "Orange Cards." These forms, which must be signed by a physician and printed on orange paper to have legal effect, inform emergency medical personnel to withhold life-saving measures in the event that cardiac or respiratory arrest occurs. Presenting this document to medical personnel means that the person is ready to die and understands that death may result if resuscitation is withheld. NOTE: The Pre-Hospital Medical Care Directive is a standardized form that must be printed on orange paper and signed by a physician to be valid. A recent photo of the person should be attached to the form.

Durable Mental Health Care Power of Attorney

A Durable Mental Health Care Power of Attorney allows a person to appoint another individual—an "agent"—to make mental health care decisions on his or her behalf if he or she becomes unable to do so. NOTE: This document can be helpful for someone with a mental illness or a disease-related dementia where institutional mental health services may be needed in the future. Mental health institutional placements are not covered by a regular Health Care Power of Attorney and require a court proceeding—unless a Mental Health Care Power of Attorney has been prepared ahead of time.

Financial Power of Attorney

The Financial Power of Attorney allows a person to appoint another individual—an "agent"—to manage financial matters on his or her behalf. These matters can include making business and property decisions. The agent may only make decisions that benefit the person involved and the agent cannot personally benefit from the Power of Attorney unless there is language in the document that specifically allows it.

Guardianship

Guardianship is the result of a legal court proceeding that removes decision-making power from an individual who is deemed to be incapacitated and transfers it to another individual—a "guardian." The guardian is appointed by the court to make all decisions for the incapacitated person, the same way a parent makes all decisions for child.

Conservatorship

A conservatorship is the result of a legal court proceeding that removes financial decision-making power from an individual who is deemed unable to make financial decisions for him or herself and transfers it to another individual—a "conservator."

Fiduciary

A fiduciary is a person who accepts responsibility for taking care of the needs or property of another person for the benefit of that person. A public fiduciary is a county official who has statutory responsibility to assume guardianship of incapacitated persons who have no one to assume this role for them. A private fiduciary is a person who has been certified or licensed to serve as a personal guardian or conservator.

Surrogate Decision Makers (Statute 36-3231)

If a person becomes unable to make or communicate health care treatment decisions and has not prepared an advance directive, a surrogate decision-maker can make health care decisions on his or her behalf. If willing and available, the following individuals can serve as surrogates regarding treatment decisions (in order of priority): spouse (unless legally separated), adult child, parent, domestic partner, sibling, a close friend or the attending physician.

Resources

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

Pathfinder: Definitions of Legal Documents Revised 06/2014

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Advance Directives

Helping older relatives or friends make more informed choices about medical care and/or financial decisions.

Frequently Asked Questions about Advance Directives

As a caregiver, I can see the changes in my loved one that indicate it may be time for help with medical and financial decisions, but I am not sure where to begin.

As a caregiver, do I need formal documents to be able to make financial or medical decisions or can I just take charge?

You cannot take charge of your relative's financial or medical decisions without permission. In your role as caregiver, you can provide assistance in a number of ways – but only up to a point. Depending on the type of assistance needed, a power of attorney or other legal authority might be required. As a caregiver, it is important that you understand the nature and consequences associated with these powers. Keep in mind that a caregiver is not obligated to assume this responsibility.

What is Power of Attorney?

A power of attorney is a powerful tool that allows one individual to appoint another individual to act on his/her behalf. The individual granting the authority is called the "principal" and the individual acting at the principal's request is known as the "agent" or "attorney-in-fact."

Since 1997, Arizona law requires that a power of attorney be used solely for the benefit of the principal and prohibits the agent from benefiting as a result of the power of attorney, The power of attorney does not create an authority to act against the wishes of the principal. If the agent disagrees with the principal, it is the principal whose instructions should be followed. This means that an agent cannot and should not go against the express wishes of the principal.

In order to allow an agent to act on behalf of someone who was competent when he or she created the power of attorney but is no longer competent, a Power of Attorney must contain some language that makes it **"durable."** A "Durable Power of Attorney" is one that contains words such as "this power of attorney shall not be affected by my disability or lack of mental competence" and the power will remain in effect even if the principal becomes disabled or incompetent. This should not be interpreted to mean that an agent can act against the wishes of the principal, but merely that he/she can act should the principal be unable to act.

Where and how does a caregiver start when concerned about a relative's ability to adequately handle finances and medical decisions?

Begin by asking your relative if he or she has already prepared documents that designate another person to assist him or her with medical and financial decisions. If your relative has not, open a discussion to determine if he or she is willing to accept assistance from you. Keep in mind that all adults have the right to refuse assistance, even if doing so may not be in his or her own best interest.

Power of attorney forms are available at many office supply stores, as well as online, and can be filled out without an attorney. Health Care POA, Living Will, Mental Health POA, and Pre-Hospital Medical Directive forms are available on the Arizona Attorney General's website at www.azag.gov/seniors/life-care-planning. Pima Council on Aging recommends hiring an attorney for help with Financial POA forms because of the potential for abuse and/or mismanagement and because an attorney can explain the positive and negative aspects of powers of attorney. Your relative's bank may also have their own specific forms to be completed to designate who can handle the bank account on your relative's behalf and under what circumstances.

For a list of attorneys who specialize in Elder Law, call Pima Council on Aging at (520) 790-7262. You can also meet with an attorney for 30 minutes at a cost of $35 though the Lawyer Referral Service. Call (520) 623-4625.

What if my relative cannot find the previously prepared documents or does not remember if he or she has any?

Obtain permission from your relative to contact family members, friends, physicians, and his or her attorney to see if anyone can confirm the existence of these documents.

What if my relative does not have a Power of Attorney?

A person must understand the meaning of the Advance Directive forms at the time he or she signs them for the documents to be valid. If your relative is no longer competent to appoint a POA or manage his or her own affairs, there may be other alternatives such as Representative Payee programs or using the medical surrogate statutes to help care for the principal. In some cases, a guardianship, which requires court approval, may be the only alternative once the principal is determined to no longer be competent. If there is any question as to the competency of the principal, be sure that documentation of competency such as letters from the principal's doctor or other witnesses are maintained.

If a person has Power of Attorney documents, why would a Guardianship proceeding be necessary?

Power of Attorney documents are very helpful, but only as long as the person agrees to cooperate. If the person has prepared these directives but chooses not to comply with the plan or decisions being made by the "agent," then it may become necessary to Petition for Guardianship. A Guardianship is a formal court proceeding. The person must be notified of the hearing and an attorney appointed to present his or her point of view to the court. If the court finds the person unable to make or communicate responsible decisions, a Guardian or Conservator is appointed to manage the person's affairs even if he or she objects to the decisions.

What if my relative wants to change his or her Power of Attorney or Living Will?

If your relative changes his or her mind about the power of attorney, he or she can revoke it by filling out a Revocation of Power of Attorney form, having it notarized, and then providing copies of it to the now-former representative and any health care providers, banks or other institutions that received a copy of the original paperwork. Your relative can then complete and distribute new documents indicating his or her current wishes.

Resources

For a list of attorneys who belong to the Tucson Chapter of the National Academy of Elder Law Attorneys (NAELA), contact Pima Council on Aging: (520) 790-7262.

Arizona Office of the Attorney General, Life Care Planning Information & Documents:
(602) 542-2124 or www.ag.state.az.us.

Lawyer Referral Service: (520) 623-4625

Alternatives to Guardianship

Direct Deposit-Automatic Bill Pay

Benefits

a. Paying bills is a frequent issue
b. Social Security requires direct deposit anyway
c. Assures the money is in the account
d. Direct pay on recurring bills saves time and postage and makes sure utilities, rent or mortgage are always paid

Joint Accounts

Benefits

a. "And" accounts require two signatures
b. Simplifies bill paying for family members when the client becomes incapacitated.

Risks

a. Any person named on a joint or convenience account can empty the account

Durable Financial Power of Attorney

Advantages

a. Avoids guardianship
b. Cuts costs
c. Helps family members

Disadvantages

a. Lack of monitoring
b. Unclear standards for agent conduct
c. Lack of awareness of risk
d. Broad decision-making authority

Representative Payee

a. Social Security or Veterans Administration
b. Provides due-process protection
c. The doctor must provide verification of incapacity
d. Notice to the beneficiary
e. SSA makes the appointment

Trusts

a. Trust is an entity that can own, buy, sell and manage assets.
b. A trust can provide for successor trustees and set conditions for trustees taking over.
c. A trustee is less likely to be challenged in legal authority.

Money Management Services

a. PCOA has a money management program.
b. Clients must agree to it, and can leave the program anytime they want to.
c. Money-managers are not decision makers.

Elder Abuse, Neglect and Exploitation

The Adult Protective Services (APS) statutes define the allegations that APS is mandated to investigate as:

Abuse: The intentional infliction of physical harm. This includes, injury caused by negligent acts or omissions, unreasonable confinement and sexual abuse/assault.

Signs & Symptoms of abuse include but are not limited to:

- Bruises, black eyes, welts, lacerations, and rope marks
- Bone fractures, broken bones, and skull fractures
- Open wounds, cuts, punctures, untreated injuries in various stages of healing
- Sprains, dislocations, and internal injuries/bleeding
- Broken eyeglasses/frames, physical signs of being subjected to punishment, and signs of being restrained
- Laboratory findings of medication overdose or under-utilization of prescribed drugs
- An elder's report of being hit, slapped, kicked, or mistreated
- An elder's sudden change in behavior
- The caregiver's refusal to allow visitors to see an elder alone
- Injury not cared for properly or delays in seeking care or treatment
- Unexplained injuries in places they would not be expected, or in the shape of an object, such as a hand, cord, iron, etc.
- Explanation of injuries not consistent with the injury or its location

Signs and symptoms of sexual abuse include but are not limited to:

- Bruises around the breasts or genital area
- Unexplained venereal disease or genital infections
- Unexplained vaginal or anal bleeding
- Torn, stained, or bloody underclothing
- An elder's report of being sexually assaulted or raped

Neglect: A pattern of conduct without the person's informed consent resulting in deprivation of food, water, medication, medical services, shelter, cooling, heating or other services necessary to maintain minimum physical or mental health.

Sign and symptoms of neglect include but are not limited to:

- Dehydration, malnutrition, untreated bed sores, and poor personal hygiene
- Unattended or untreated health problems
- Hazardous or unsafe living condition/arrangements (e.g., improper wiring, no heat, or no running water)

- Unsanitary and unclean living conditions (e.g. dirt, fleas, lice on person, soiled bedding, fecal/urine smell, inadequate clothing)
- An elder's report of being mistreated

Exploitation: The illegal or improper use of an incapacitated or vulnerable adult or his/her resources for another's profit or advantage.

Signs & symptoms of exploitation include but are not limited to:

- Sudden changes in bank account or banking practice, including an unexplained withdrawal of large sums of money by a person accompanying the elder
- The inclusion of additional names on an elder's bank signature card
- Unauthorized withdrawal of the elder's funds using the elder's ATM card
- Abrupt changes in a will or other financial documents
- Unexplained disappearance of funds or valuable possessions
- Substandard care being provided or bills unpaid despite the availability of adequate financial resources
- Discovery of an elder's signature being forged for financial transactions or for the titles of his/her possessions
- Sudden appearance of previously uninvolved relatives claiming their rights to an elder's affairs and possessions
- Unexplained sudden transfer of assets to a family member or someone outside the family.
- The provision of services that are not necessary
- An elder's report of financial exploitation
- The alleged victim is being asked to sign financial documents, e.g., Powers of Attorney
- The victim may show up to the bank with an individual who is waiting outside while the client withdraws cash

Vulnerability: A mental or physical impairment that prevents the vulnerable adult from protecting themselves. The person lacks sufficient understanding to make or communicate informed decisions. At times it could be due to mental illness, physical illness or chronic use of drugs or intoxication.

Signs & Symptoms of vulnerability include but are limited to:

- The vulnerable adult does not understand his/her situation
- The vulnerable adult is not realistic about the consequences of his/her situation
- The vulnerable adult is unaware of resources and unable to access resources due to dementia/confusion or other impairments
- The vulnerable adult is dependent on others for his/her care or management of finances

The following two allegations are not in the APS statutes but are investigated through internal policy authority.

Self-Neglect: (This is not a legal definition): An adult's inability due to physical or mental impairment or diminished capacity, to perform essential self-care tasks, including:

- Obtaining essential food, clothing, shelter, and medical care
- Obtaining goods and services necessary to maintain physical health, mental health or general safety
- Managing one's own financial affairs

Signs & symptoms of self-neglect include but are not limited to:

- Dehydration, malnutrition, untreated or improperly attended medical conditions, and poor personal hygiene
- Hazardous or unsafe living conditions/arrangements (e.g., improper wiring, no indoor plumbing, no heat, no running water)
- Unsanitary or unclean living quarters (e.g., animal/insect infestation, no functioning toilet, fecal/urine smell)
- Inappropriate and/or inadequate clothing, lack of the necessary medical aids (e.g., eyeglasses, hearing aids, dentures)
- Grossly inadequate housing or homelessness

Emotional Abuse: A pattern of ridiculing or demeaning a vulnerable adult, making derogatory remarks to a vulnerable adult, verbally harassing a vulnerable adult or threatening to inflict physical or emotional harm on a vulnerable adult.

Signs & symptoms of emotional abuse include but are not limited to:

- Verbal assaults, insults, threats, intimidation, humiliation, and harassment
- Isolating an elderly person from his/her family, friends, or regular activities
- Being extremely withdrawn and non-communicative or non-responsive
- An elder's report of being verbally or emotionally mistreated

What is the best way to make a report? Online reporting: www.azdes.gov/reportadultabuse

- Available 24 hours a day, 7 days a week
- Enter report at your own pace
- No waiting for next available agent
- Report is in your own words

Telephone reporting: (877) 767-2385

- Talk to a live person
- Can make anonymous report
- Will receive feedback about your report (accepted or not)
- Monday-Friday 7am - 7pm / Sat-Sun 10am - 6pm

What should a person expect when he or she makes a report?

The reporter will be asked a multitude of questions about:

- The vulnerable adult (potential victim)
- The alleged perpetrator
- Significant others
- Reporting source
- Dangerous animals, weapons, diseases, etc.
- Description of incident (abuse, neglect and/or exploitation)
- How is the client vulnerable (what prevents the victim from protecting themselves?)

What are the criteria that would lead APS to launch an investigation?

The client is being abused, neglected or exploited and is vulnerable.

When would APS decline to launch an investigation?

When there are no allegations and the client has no vulnerability that prevents him/her from protecting him/herself.

What type of feedback should the person making the report expect?

Whether the case will be accepted for investigation or not.

What principles or examples might make clear to an individual when a report should not be made?

- Suicide threat/attempts (should be reported to law enforcement)
- Theft as opposed to exploitation
- The adult is not vulnerable
- Psychotic behavior, i.e. hallucinations, delusions, etc. (these types of situations should be referred to a mental health agency/crisis team)

Is there a second level of reporting if an individual is concerned that his or her report was not handled appropriately?

- Hotline supervisor: 602-542-4307.
- APS Operations Manager: 602-364-1567
- Program Administrator: 602-542-6459.

How do APS and local law enforcement collaborate?

APS makes referral to law enforcement.

APS works closely with law enforcement by conducting joint investigations and sharing case information At times law enforcement will request that APS not interview certain individuals in an investigation until they do.

Is there ever a time when the reporter should go to law enforcement rather than APS?

All crimes should be reported to law enforcement due to the critical and essential need to preserve evidence. Law enforcement and APS do not have the same burden of proof and the burdens of proof are for different purposes.

- APS has a Preponderance of Evidence (burden of proof) which is used to substantiate cases and move forward with the due process for the alleged perpetrator. The due process consists of an Administrative Hearing for the alleged perpetrator to see if the hearing officer affirms the APS findings so that the perpetrators name is placed on the APS Registry for 10 years.
- Law enforcements' burden of proof is much higher due to the possibility of criminal charges and prosecution.

Are there consequences for mistreatment of vulnerable adults?

Aside from Criminal and Civil penalties, anyone with a substantiated case of mistreatment could potentially have his/her name placed on the APS Central Registry. The case may go before an Administrative Law Judge for determination of the substantiation. If it is affirmed, the accused person's name will be placed on a Central Registry for 10 years, which is open to the general public upon written request for the information. Potential employers could request information about an individual they are considering for hire, therefore impacting a person's employment.

Who is required to report mistreatment of vulnerable adults?

By law, a physician, registered nurse practitioner, hospital intern or resident, surgeon, dentist, psychologist, social worker, peace officer or other person who has responsibility for the care of a vulnerable adult and who has a reasonable basis to believe that abuse or neglect of the adult has occurred or that exploitation of the adult's property has occurred shall immediately report or cause reports to be made of such reasonable basis to a peace officer or to a protective services worker. The guardian or conservator of a vulnerable adult shall immediately report or cause reports to be made of such reasonable basis to the superior court. All of the above reports shall be made immediately in person or by telephone and shall be followed by a written report mailed or delivered within forty-eight hours or on the next working day if the forty-eight hours expire on a weekend or holiday. The report source will be held confidential, except as provided by law and reporters are immune from civil or criminal liability unless the report was made in bad faith or with malice.

What are the limitations of APS?

- While APS will attempt to assist the victim to alleviate mistreatment, prevent further harm, and seek community resources, APS does not have the authority to take custody of an adult or his/her finances.
- APS cannot remove the adult from his/her environment (living situation) against his/her will or require the adult to accept services, including Adult Protective Services.
- APS staff cannot serve as guardian/conservator.

Source: Adult Protective Services www.azdes.gov/daas/aps

Watchdog Alert

October 17 2013

FRAUD WATCH NETWORK
Brought to you by AARP

Protect Yourself from Identity Theft & Fraud

There are a number of things you can do to protect you and your loved ones from online or offline identity theft and fraud:

Protect Your Social Security Number (SSN) & Personal Information

- Don’t carry your Social Security card in your wallet.
- Don’t print your SSN or driver’s license number on your checks.
- Shred sensitive information.
- Limit the number of credit cards you carry.
- Keep copies of credit cards (front and back) in a safe place in case a card is lost or stolen.

Monitor Your Bills & Financial Accounts

- Watch for missing bills and review your monthly statements carefully.
- Contact your creditors if a bill doesn’t arrive when expected or includes charges you don’t recognize.
- Don’t invest in anything you are not absolutely sure about. Do your homework on the investment, the company, and the salesperson to ensure that they are legitimate. You can look them up at finra.org/BrokerCheck and sec.gov.

Watch Over Your Credit Reports

- You are entitled to one free credit report each year from each nationwide credit bureau. To get your free report, go to annualcreditreport.com or call 1-877-322-8228.

Protect Personal Identification Numbers (PINS) & Passwords

- Don’t carry your PINS and passwords in your wallet or purse.
- Avoid using easily available information for your PINs or passwords such as your mother’s maiden name, your or a family member's birth date, your SSN or phone number, or a series of consecutive numbers (i.e., 1, 2, 3, 4).
- Choose a different PIN for each account.

Watchdog Alerts / Tips & Resources / Free for Everyone

FRAUD WATCH NETWORK™

Protect Your Information Online

⇒ Beware of emails that claim to come from a bank, Internet Service Provider, business or charity and ask you to confirm your personal information or account number. If you receive one that is suspicious, forward the email to spam@uce.gov.

⇒ Avoid conducting personal or financial business on shared/public computers or over public wireless hotspots.

⇒ Install the latest version of established anti-virus software.

⇒ Make sure websites are secure, especially when shopping online. A secure website will begin with “https” not the usual “http”.

Protect Your Mail

⇒ Call 1 (888) 5-OPT-OUT or visit optoutprescreen.com to stop pre-approved credit card applications that a thief could steal and use to get credit in your name.

⇒ Place outgoing mail into a locked mailbox such as a blue postal service box.

⇒ Don’t leave incoming mail sitting in an unlocked mailbox.

⇒ Cut down on junk mail by contacting the Direct Marketing Association at dmachoice.org.

Be Cautious of Scams & Frauds

⇒ Never give personal information to telemarketers who call you on the phone. To cut down on unwanted telemarketing calls, sign up for the Do Not Call Registry at donotcall.gov or call (888) 382-1222.

⇒ Double-check references for door-to-door sales, home repair offers and other products. Verify that businesses and others who contact you are who they claim to be before you provide any personal information. If you think the request for information is legitimate, contact the company at a number you know is valid to verify the request.

⇒ Check out a charity before donating to make sure they are legitimate at charitywatch.org or charitynavigator.org.

For more information about the latest scams, visit:

aarp.org/fraudwatchnetwork

Who to Contact

There are a number of places you can turn to if you or someone you love has been a victim of fraud or identity theft or if you are just looking to learn more about how to safeguard against them:

Fraud Watch Network

The AARP Fraud Watch Network provides you with access to information about identity theft, investment fraud and the latest scams. Access online at: **aarp.org/fraudwatchnetwork**

Fraud Fighter Call Center

Highly trained AARP volunteer Fraud Fighters are standing by to offer peer counseling, support and referral services to fraud victims and their family members. Call toll-free: **877-908-3360**

The National Association of Attorneys General (NAAG)

The NAAG site provides contact information for all state attorneys general. Most state attorneys general welcome consumer inquiries and complaints about frauds occurring in the marketplace and many offer complaint mediation services as well. Access online at: **naag.org**

FINRA Investor Education Foundation

The FINRA Investor Education Foundation provides critical information about how to avoid investment fraud, including allowing you to check to see if a broker or a particular investment advisor is registered. It is particularly helpful in addressing a variety of investment frauds such as gold coins and oil and gas scams. Access online at: **saveandinvest.org**

The North American Securities Administrators Association (NASAA)

This website is where you can find your local state securities regulator, who takes complaints against brokers and dealers that may have engaged in investment fraud. Find your regulator online at: **nasaa.org**

U.S. Postal Inspection Services

This site, sponsored by the U.S. Postal Inspection Service, has information about how to protect yourself from mail fraud and how to identify when you've been targeted. Access online at: **deliveringtrust.com**

Federal Trade Commission (FTC) Consumer Help

Call the Federal Trade Commission to file a complaint against a company if you feel you have been defrauded. Call toll-free **877-701-9595** or visit **ftccomplaintassistant.gov**

Securities and Exchange Commission (SEC)

The SEC is a good resource for checking up on an investment adviser and investment products. Call toll-free **800-SEC-0330** or visit **sec.gov/investor** or **investor.gov**

Consumer Financial Protection Bureau

If you have a complaint about fraudulent activity involving a bank account or service, credit reporting, debt collection, among other areas, contact the CFPB to file a complaint. File online at: **consumerfinance.gov/complaint**

National Association of Insurance Commissioners

Visit the NAIC website if you want to reach a state insurance agency about an insurance product or salesperson. Find your state at: **naic.org/state_web_map**

Commodity Futures Trading Commission (CFTC)

The CFTC can assist with problems in commodity futures, precious metals, and foreign currency trading. Call **866-366-2382** or visit **cftc.gov/consumerprotection**

FRAUD WATCH NETWORK™
AARP Real Possibilities

Section 12

Community Resources for Caregivers

CAREGIVER CONSORTIUM

A Guide to Services
2014

Directory of Aging and Disability Resources in Pima County

PCOA
PIMA COUNCIL ON AGING
Advocacy, Action, Assistance

Pima Council on Aging
8467 E. Broadway ▪ Tucson, AZ 85710 ▪ www.pcoa.org
Help Line: (520) 790-7262 or help@pcoa.org

Pima County Resources

Activities for Seniors

Call PCOA for a complete list of activities and clubs	(520) 790-7262
Adventure Bus at Handmaker’s	(520) 547-6007
Computer Adult Learning Centers	(520) 721-7591
Elder Circles	(520) 298-6542
Elder Circles for the homebound	(520) 298-6542
Osher Lifelong Learning Institute	(520) 626-9039
Parks and Recreation Centers	(520) 791-4877
Pima Community College	(520) 206-4500
Pima Council on Aging’s Living Well Program	(520) 790-7262
Savvy Seniors Stretching and Strengthening	(520) 296-6149
Senior Circle at Northwest Hospital	(520) 901-3631
Senior Moments	(520) 297-3095
The Drawing Studio OATS Program	(520) 622-0947
The Learning Curve	(520) 777-5817
TMC Senior Services	(520) 324-1960
Tucson Chinese Cultural Center Programs	(520) 292-6900

Meals and Socialization

Archer Center	(520) 791-4355
Armory Park Senior Center	(520) 791-4070
Casa Community Center	(520) 393-6814
Eastside El Dorado	(520) 546-2257
El Pueblo Neighborhood Center	(520) 889-0928
El Rio Neighborhood Center	(520) 837-8210
Ellie Towne/Flowing Wells	(520) 887-9786
Freedom Recreation Center	(520) 791-4969
Donna Liggins Center	(520) 791-3247
Quincie Douglas Senior Center	(520) 791-2509
William Clements Regional Center	(520) 791-5787
Robles Junction Community Center	(520) 822-4408
Arivaca Coordinating Council	(520) 398-2771
Catalina Community Services	(520) 825-0009
Picture Rocks Community Center	(520) 682-7166
Liogue Senior Center	(520) 879-5530
Las Comadritas at the House of Neighborly Service	(520) 323-1708

Adult Day Care

Casa Community Services (Green Valley)	(520) 625-2273
Handmaker’s Adult Day Care	(520) 547-6037
Senior Moments Adult Day Care (Vail)	(520) 561-0448
Home Health Companion Services (Call PCOA for list)	(520) 790-7262

ALS Resources

ALS Association—Arizona	(866) 350-2572
Banner Health Meds Connection	(866) 995-6432
Emory ALS Center (Atlanta)–Multidisciplinary Treatment	(404) 727-6123

Alzheimer's and Related Dementias

Alzheimer's Association Helpline	(800) 272-3900
Alzheimer's Association Tucson Office	(520) 322-6601
Clinical Trials	(800) 272-3900
PCOA Caregiver Specialists (Caregiver Resources)	(520) 790-7262
Support Groups	See listing under **"SUPPORT GROUPS"**

Neuropsychological Evaluations

David Hermosillo-Romo PhD	(520) 690-6443
Neuropsychology, LTD	(520) 352-9955
Southern Arizona Neuropsychology Associates	(520) 329-8298
UAMC Behavioral Neuroscience and Alzheimer's Clinic	(520) 626-6524

Locating Devices for Wanderers

Alzheimer's Association Comfort Zone	(800) 272-3900
Alzheimer's Association Comfort Zone Check In	(800) 272-3900
Desert Tracker GPS	(520) 838-1130
Medic Alert®	(800) 272-3900
5Star Urgent Response	(800) 918-8543

Alzheimer's and Dementia Support Groups

Support Group—Alzheimer's Association	(520) 322-6601
Support Group—Civano Business Center Board Room	(520) 322-6601
Support Group—Clare Bridge of Oro Valley	(520) 322-6601
Support Group—Continental Reserve Urgent Care	(520) 322-6601
Support Group—Emeritus at Catalina Foothills	(520) 322-6601
Support Group—Grace Health and Healing	(520) 322-6601
Support Group—Green Valley Community Church	(520) 322-6601
Support Group—Pacifica Senior Living	(520) 322-6601
Support Group—Lutheran Church (Green Valley)	(520) 322-6601
Support Group—Northminster Presbyterian (	(520) 322-6601
Support Group—Northwest Oro Valley Hospital	(520) 322-6601
Support Group—Oro Valley Public Library	(520) 322-6601
Support Group—Pima Council on Aging	(520) 322-6601
Support Group—Rancho Resort	(520) 322-6601
Support Group—Rancho Vistoso	(520) 322-6601
Support Group—Santa Catalina Villas	(520) 322-6601
Support Group—TMC Senior Services	(520) 322-6601
Support Group—Valley Presbyterian Church (Green Valley)	(520) 322-6601
Support Group—Veteran's Hospital (Respite available)	(520) 322-6601
Support Group—Voyager RV Resort	(520) 322-6601

Amputee Resources

Amputee Coalition	(888) 267-5669
Freedom Innovations	(888) 818-6777
Hanger Prosthetics and Orthotics	(877) 442-6437

Support Groups

Amputee Support Group	(520) 873-3661

Appliances—Low Cost

HabiStore Home Improvement Center	(520) 889-7200
Re-Store, TMM Family Services, Inc	(520) 326-1936

Arizona Long Term Care System (ALTCS)

Arizona Long Term Care System (ALTCS)	(520) 205-8600
ALTCS Workshops (Call PCOA for information)	(520) 790-7262
ALTCS Questions (Call PCOA)	(520) 790-7262
ALTCS Facilities (Call PCOA for lists)	(520) 790-7262

Arthritis Resources

Arthritis Foundation—Arizona	(602) 264-7679
Tucson Arthritis Support League	(520) 324-1053

Assisted Living Facilities and Adult Care Homes

Call PCOA for lists	(520) 790-7262
PCOA Long-Term Care Ombudsmen (Advocacy)	(520) 790-7262

Assisted Living—Low-Income

Marshall Home for Men	(520) 624-5193
St Luke's Home	(520) 628-1512

Assistive Equipment & Medical Supplies

Arizona Superior Medical Program (Medical Monitoring)	(520) 747-7403
Home Adaptation Specialists (Call PCOA for list)	(520) 790-7262
DIRECT Center for Independence (Disabled clients only)	(520) 624-6452
Friends In Deed (Green Valley)	(520) 625-1150
Guardian Medical Monitoring	(520) 906-0232
Lockboxes for Fire Dept, Access (Call PCOA for list)	(520) 790-7262
New Spirit Lutheran Church (Medical Equipment Loans)	(520) 731-3706
Southern Arizona Lifeline Systems	(520) 465-4111
Salvation Army (Main Store)	(520) 624-1741
Top Dog Training (Dog Training for the Disabled)	(520) 323-6677
Handi-Dog	(520) 326-3412
Tucson Urban League Community Closet	(520) 791-9522

Cancer Resources

American Cancer Society	(800) 227-2345
American Cancer Society (Tucson Office)	(520) 321-7989
Cancer Matters	(913) 385-7332
Housekeeping Help	www.cleaningforareasonorg
Road to Recovery (Rides to doctor appointments)	(520) 321-7989
Susan G Komen Southern Arizona (Breast cancer)	(520) 319-0155
Free Wig Trims and Head Shaves (call PCOA for list)	(520) 790-7262
UAMC Cancer Center (Support Groups)	(520) 624-2873

Caregiver Resources

Call Pima Council on Aging	(520) 790-7262
Caring Information	www.caring.com
Caregiver Consortium (local resources)	www.caregiverconsortium.org
Caregivers Handbook	www.pcoa.org

Children of Aging Parents	www.CAPS4caregivers.org
Empowering Caregivers	www.care-givers.com
Family Caregiver Alliance	www.caregiver.org
National Family Caregivers Association	www.caregiveraction.org

Caregiver Support Groups

Caregiver Support—Northwest Tucson	(520) 609-1271
Caregiver Support—Oro Valley	(520) 609-1271
Caregiver Support—East Tucson	(520) 609-1271
Caregiver Support—Green Valley	(520) 609-1271
Caregiver Support—Central Tucson	(520) 609-1271
Caregiver Support—North Tucson	(520) 609-1271
Caregiver Support—Southwest Tucson	(520) 609-1271
Caregiver Support—Catalina	(520) 609-1271

Caregiver Training Programs (for employment)

CareGiver Training Institute	(520) 325-4870
Dependable Health Services	(520) 795-1290
Pima Community College	(520) 206-4500

Caregiver Training Program (for family caregivers)

Luminaria Home Care	(520) 488-7340

Case Management

For low-income disabled adults and seniors 60+

Community Services System (call for screening)	(520) 790-7262
Southern Arizona AIDS Foundation—all ages (SAAF)	(520) 628-7223
Valley Assistance (Green Valley and surrounding area)	(520) 625-5966

Private Pay—Open to all

Alternatives In Home Care	(520) 327-3384
Arizona Care Advocates	(520) 302-8962
Care Coordinators, Inc	(520) 325-8881
Caring Cooperatives	(520) 631-0961
Jewish Family & Children's Services	(520) 795-0300
Organizing Helpers	(520) 327-8586
Our Family Services	(520) 323-1708
Patient Care Advocates	(520) 546-4141

COPD Resources

American Lung Association	(800) 586-4872
COPD Alliance	(847) 498-8123
COPD Foundation: COPD Information Line	(866) 316-2673
Support group	(520) 323-1812

Counseling/Mental Health

Crisis Line (24 hour help)	(520) 622-6000
MHC Behavioral Health Services	(520) 682-1091
Casa Community Services (Green Valley crisis line) (520) 625-2273	
Catalina Community Services (Catalina area	(520) 825-0009
Catholic Social Services	(520) 623-0344 ext 1014

CODAC Behavioral Health	(520) 327-4505
COPE Behavioral Services	(520) 792-3293
Community Partnership of Southern Arizona (CPSA)	(520) 325-4268
Depression and Bipolar Support Alliance	(520) 531-2388
Eldercare Mediation (Our Family Services)	(520) 323-1708
HOPE Warm Line (Mental Illness or Addiction)	(520) 770-9909
Jewish Family and Children's Services	(520) 795-0300
KARE (for grandparents raising grandchildren)	(520) 323-4476
La Frontera (Behavioral Health)	(520) 884-9920
Lutheran Social Services of the Southwest	(520) 748-2300
Marana Health Center	(520) 682-4111
National Alliance on Mental Illness (NAMI of S AZ)	(520) 622-5582
Our Family Services	(520) 323-1708
Pasadera Behavioral Health Network	(520) 617-0043
University of Phoenix Counseling Skills Center	(520) 239-5315
Veteran's Crisis Line	(800) 273-8255

Domestic Violence Resources

Administration of Resources and Choices	(520) 623-3341
Emerge Center Against Domestic Abuse	(520) 795-4266
Family Law Free Legal Help	(520) 740-8456
Southern Arizona Legal Aid, Inc	(520) 623-9465
Wingspan Anti-Violence Project	(520) 624-0348

Geriatric Psychiatrists

Adult Psychiatry Clinic (Campbell)	(520) 626-7664
Adult Psychiatry Clinic (Ajo Way)	(520) 874-7523
Aleph Center	(520) 885-5558
Behavioral Health Pavilion	(520) 874-7500
Dr Bennett Blum (Elder abuse, financial exploitation)	(520) 750-8868
Dr Lawrence Cronin and Dr Marla Reckart	(520) 751-8500
Dr Irene Kitzman	(520) 203-8500
Dr Raul Sora	(520) 750-1739
Dr Dennis Westin and Dr Marshall Jones	(520) 795-0309

Dental Clinics—Reduced Fee

El Rio Dental Clinics	(520) 670-3758
Desert Senita Medical Center (Ajo)	(520) 387-4500
Marana Dental Clinic	(520) 616-6200
Pima Community College (Cleanings only)	(520) 206-6090
St Elizabeth of Hungary Dental Clinic	(520) 628-7871
Urgent Care Dental (Extractions only)	(520) 322-5800

Diabetes Self-Management

PCOA Diabetes Self-Management Program	(520) 790-7262
Carondelet Community Classes—St Joseph's	(520) 873-3968
Carondelet Community Classes—St Mary's	(520) 872-6055
Diabetes Life Skills Center	(520) 742-2121
TMC Diabetes Education Program	(520) 324-2075
TMC Journey for Control	(520) 324-1960
YMCA Diabetes Prevention (Pre-Diabetes only)	(520) 623-5511 ext 218

Diabetes Support Groups

Support Group—St Joseph's Hospital	(520) 873-3968
Support Group—St Mary's Hospital	(520) 872-6055
Support Group—Green Valley	(520) 872-6055

Disability Resources

DIRECT Center for Independence	(520) 624-6452
Aging and Disability Resource Center	www.azlinks.gov

Emergency Alert Systems

Arizona Superior Medical Program (Medical Monitoring)	(520) 747-7403
Guardian Medical Monitoring	(520) 906-0232
Southern Arizona Lifeline Systems	(520) 465-4111
Safe Return Program (through the Alzheimer's Assoc)	(520) 322-6601
5Star Urgent Response	(520) 918-8543

End of Life

Funeral Consumers Alliance	(520) 721-0230
Grief Support Groups (Call PCOA for list)	(520) 790-7262
Passages: Support and Education in End of Life Issues	(520) 400-0274
Hospice	See listing under "HOSPICE"

Body and Organ Donation

Biogift	(866) 670-1799
Donor Network of Arizona	(800) 943-6667
Life Legacy	(520) 575-5200
Mayo Clinic	(507) 284-2693
Science Care	(800) 417-3747
UAMC Willed Body Program	(520) 626-6083
United Network for Organ Sharing (UNOS)	(888) 894-6361

Financial Assistance

PCOA Budgeting Assistance (Call PCOA for eligibility)	(520) 790-7262
Western States Pension Assistance Project (Counseling)	(866) 413-4911
Benefits Check-Up	www.benefitscheckup.org

Fiduciaries and Representative Payees

Above and Beyond	(520) 903-1733
Arizona Care Advocates	(520) 302-8962
Care Coordinators	(520) 325-8881
Caring Cooperatives	(520) 631-0961
Jewish Family & Children's Services	(520) 795-0300
Organizing Helpers	(520) 327-8586
Payees Plus	(520) 395-1599
Sandra Paz	(520) 207-3484
Personal Support Services	(520) 615-0360
Project Home	(520) 885-7084
Pima County Public Fiduciary	(520) 740-5454
Social Security Services of Arizona	(877) 604-1065
Zimmerman's Personal Agents	(520) 531-9051

Foreclosure Prevention Help

Administration of Resources and Choices	(520) 623-9383
Chicanos por la Causa	(520) 882-0018
Don't Borrow Trouble	(520) 792-3087
Family Housing Resources	(520) 318-0993
Money Management International	(800) 308-2227
New Life Community Resource Center	(520) 889-8225
Old Pueblo Community Services	(520) 546-0122
Pio Decimo Center	(520) 624-0551
Primavera Foundation	(520) 395-6420
TMM Family Services	(520) 322-9557
Tucson Urban League	(520) 791-9522

Rent and Mortgage Assistance—Within Tucson City Limits

Help is limited to one time per year

Tucson Urban League	(520) 791-9522

Rent and Mortgage Assistance—Outside Tucson City Limits

Help is limited to one time per year

Pima County Community Action Agency	(520) 243-6688
Arizona Housing and Prevention Services	(520) 498-4613
Chicanos Por La Causa	(520) 882-0018
Interfaith Community Services	(520) 297-6049
Project PPEP	(520) 622-3553
Primavera Foundation	(520) 395-6420
Salvation Army	(520) 792-1111

Utility Assistance—Within Tucson City Limits

Tucson Urban League	(520) 791-9522

Utility Assistance—Outside Tucson City Limits

Arivaca Coordinating Council	(520) 398-2771
Catalina Community Services	(520) 825-8288
Greater Littletown Human Resources Group	(520) 574-2263
Interfaith Community Services Eastside	(520) 731-3076
Interfaith Community Services Northside	(520) 297-6049
Picture Rocks Community Center	(520) 682-7166
Salvation Army	(520) 792-1111
San Ignacio Yaqui Council	(520) 884-8527

Food Assistance

General Food Assistance

Ajo Food Bank	(520) 387-4916
Casa Community Services (Green Valley Senior Center)	(520) 625-2273
Catalina Community Services (Catalina only)	(520) 825-0009
Community Food Bank	(520) 622-0525
DES (Food Stamps)	(800) 352-8401
Food box distribution (Call PCOA for list)	(520) 790-7262
Food Plus for Seniors (Pima County Health Dept)	(520) 243-7777
Green Valley and Sahuarita Food Bank	(520) 625-5252

Marana Community Food Bank	(520) 628-3001
Senior Farmers Markets (Pima County Health Dept)	(520) 243-7777

Meals and Socialization

Archer Center	(520) 791-4355
Armory Park Senior Center	(520) 791-4070
Casa Community Center	(520) 393-6814
Eastside El Dorado	(520) 546-2257
El Pueblo Neighborhood Center	(520) 889-0928
El Rio Neighborhood Center	(520) 837-8210
Ellie Towne/Flowing Wells	(520) 887-9786
Freedom Recreation Center	(520) 791-4969
Donna Liggins Center	(520) 791-3247
Quincie Douglas Senior Center	(520) 791-2509
Robles Junction Community Center	(520) 822-4408
William Clements Regional Center	(520) 791-5787
Arivaca Coordinating Council	(520) 398-2771
Catalina Community Services	(520) 825-0009
Picture Rocks Community Center	(520) 682-7166
Liogue Senior Center	(520) 879-5530
Las Comadritas at the House of Neighborly Service	(520) 323-1708

Home Delivered Meals

A Culinary Affair—Personal Chef Service	(520) 797-2689
Catalina Community Services (Catalina only)	(520) 825-0009
Delicious Deliveries (restaurant deliveries)	(520) 620-6600
Dine Wise	(800) 749-1170
Groceries 2 Your Door & More	(520) 288-9310
Impact of Southern Arizona (Vail)	(520) 222-4966
Lutheran Social Services (Shopping service)	(520) 514-7642
Magic Kitchen	(877) 516-2442
Matt's Organics (Fresh produce)	(520) 790-4360
Meals by the Week	(520) 741-9020
Mobile Meals (northwest area)	(520) 297-6049
Mobile Meals (special diet meals; no age restriction)	(520) 622-1600
Mom's Meals	(866) 971-6667
Pascua Center	(520) 882-7688
Pima Meals on Wheels (through PCOA)	(520) 790-7262
Schwan's	(888) 724-9267
St Nicholas Indian Center (South Tucson)	(520) 879-5537
Westside Nutrition (Catholic Social Services)	(520) 624-1562

Government Representatives

Call PCOA for a complete list with contact information	(520) 790-7262

Grandparent Resources

Casa de los Niños Thrift Store	(520) 325-2573
Child Care Assistance	(520) 628-6810

Department of Corrections Family Liaison	(520) 364-3945
Immunizations (Pima County Health Dept)	(520) 243-7770
Family Resource & Wellness Center	(520) 545-2322
Guardianship (Call KARE Family Center)	(520) 323-4476
KARE Family Center	(520) 323-4476
Social Security Benefits	(800) 772-1213
Southern Arizona Grandparents Coalition	(520) 626-5161
Temporary Assistance for Needy Families	(520) 628-6810

Green Valley Social Service Agencies

Call PCOA for a complete Green Valley Resource list (520) 790-7262

Casa Community Services	(520) 625-2273
Friends In Deed	(520) 625-1150
PCOA Community Office (Mondays only)	(520) 625-1150 ext 108
Salvation Army	(520) 625-3888
Telecare Volunteer Program	(520) 332-4492
Valley Assistance Services, Inc	(520) 625-5966

Grief and Loss Support Groups

Call PCOA for a complete list	(520) 790-7262

Health and Exercise

Living Well with Chronic Conditions	(520) 790-7262
A Matter of Balance	(520) 790-7262
Enhance Fitness	(520) 790-7262
Healthy Living with Diabetes	(520) 790-7262
SilverSneakers®	(888) 423-4632

Hearing Loss Resources

Adult Loss of Hearing Association (ALOHA)	(520) 795-9887
Arizona Commission for the Deaf/Hard of Hearing	(800) 352-8161
Arizona Relay Service (711)	(866) 259-1768
Audient Alliance (Hearing Aid Financial Assistance)	(866) 956-5400
Caption Call Phone	(888) 699-6242
Community Outreach Program for the Deaf (COPD)	(520) 792-1906
COSTCO Hearing Aid Centers (East Tucson)	(520) 886-6377
COSTCO Hearing Aid Centers (NW Tucson)	(520) 797-1980
COSTCO Hearing Aid Centers (South Tucson)	(520) 791-7340
Hamilton Internet Relay	www.hamiltonrelay.com
HEAR NOW Program	(800) 328-8602
iCanConnect	(520) 792-1906
Project Endeavor	(800) 259-1768
U of A Hearing Aid Bank (Call COPD)	(520) 792-1906
U of A Adult Hearing Clinic	(520) 621-7070
U of A Living with Hearing Loss Support Groups	(520) 621-7070

Heart Disease

American Heart Association (Tucson)	(520) 795-1403

Hoarding Resources

General Hoarding Contacts

City of Tucson Code Enforcement	(520) 791-5843
Pasadera Behavioral Health Network	(520) 622-6000
Tucson Fire Department Prevention Unit	(520) 791-4014
Tucson Police Department	(520) 791-4444

Hoarding Clean Up

1-800-GOT-JUNK?	(520) 465-4395
Abracadabra Restoration	(520) 323-3261
Ann’s Handy Helpers	(520) 888-4996
AZ-Bio Cleanup and Restoration	(877) 292-4691
Caring Transitions of Southern Arizona	(520) 262-1495
Organizing Helpers	(520) 327-8586
Pima County Adult Probation–Community Restitution	(520) 740-4915
Pima County Community Restitution Program	(520) 740-4915
Quality Restoration	(520) 322-5326
Southwest Hazard Control	(520) 622-3607
Tracy’s Dynamic Cleaning	(520) 721-4288

Animal Hoarding Resources

88-Crime Anonymous Tip Line	(520) 882-7463
Animal Cruelty Taskforce	(520) 547-0260
Animal Experts	(520) 531-1020
Humane Society	(520) 881-0321
Pima County Animal Control	(520) 243-5900

Counseling and Support Groups

Clutterers Anonymous	www.clutterersanonymous.net
Children of Hoarders Support	www.childrenofhoarders.com
Ann Haney Gooden, LCSW	(520) 733-2524
La Frontera Center, Inc	(520) 884-9920
Dr Patricia Volkerts	(520) 325-2723

Home Care Services (In-Home Help)

Community Services System (call for screening)	(520) 790-7262
Private Pay Home Health Agencies (call PCOA for list)	(520) 790-7262
Senior Companions (Our Family Services)	(520) 323-1708

Hospital and Rehab Discharge Help

Care Transitions (Call PCOA for Information)	(520) 790-7262
Catalina In-Home Services	(520) 327-6351
ComForcare	(520) 297-4333
Hospital to Home	(520) 770-9943

Medical House Calls

Ascension In-Home Medical Care	(520) 577-1136

At Home Medical Care, LLC	(520) 940-1119
Dr Raymond Bock (Podiatry only)	(520) 881-2882
IPC	(520) 615-6200
Medical Care Solutions	(520) 408-4627
Providers Direct	(520) 722-2400
Southwest Geriatrics	(520) 314-3412

Mobile Hair Care

Angels on Earth	(520) 405-1590
FresHair Salon and Mobile Service	(520) 906-8742
Travelling Scissors	(520) 293-4740
Hunter’s Barbershop	(520) 620-1683
Ronnie Tolivar	(520) 390-0770
Susan Dayton	(520) 603-6797

Veterinary In-Home Services

Ken Cohn, DVM	(520) 471-1106
Cactus Creek Mobile Vet Service	(520) 405-3071
Homeward Bound Vet Services	(520) 668-1238
St Francis Veterinary Group	(520) 271-7660

Home Repair and Adaptation

Ajo Works Job Training Program (Ajo, AZ)	(520) 387-3570
DES Independent Living Program (Disability Adaptation)	(520) 638-2399
Chicanos por la Causa (Roof replacements)	(520) 882-0018
City of Tucson Housing and Community Development	(520) 791-4636
Community Home Repair Projects of Arizona	(520) 745-2055
DIRECT Center for Independence (Disability Adaptation	(520) 624-6452
Habitat for Humanity	(520) 326-1217 ext 224
Independent Contractors (Call PCOA for list)	(520) 790-7262
ICS (Small maintenance and repairs in limited areas)	(520) 297-6049
Jewish Elder Access	(520) 404-4596
Junior League of Tucson	(520) 299-5753
Pima Council on Aging (Home owners 60+)	(520) 790-7262
Pima Community Action Agency	(520) 243-6700
Pima County Community Development	(520) 243-6789
Town of Marana (Marana only)	(520) 382-1999
TMM Family Services	(520) 322-9557
Tucson Urban League	(520) 791-9522
Utility Repair, Replacement, and Deposit Program	(520) 243-6688
Yard Work Program	(520) 740-4915

Hospice

Agape Hospice	(520) 207-5817
Casa de la Luz	(520) 544-9890
Carondelet Hospice	(520) 205-7700
Evercare Hospice and Palliative Care	(520) 407-8000
Gentiva Hospice	(520) 577-0270
Heartland Hospice	(520) 325-2790
Hospice Family Care	(520) 790-9299

Soulistic Hospice	(520) 398-2333
TMC Hospice	(520) 324-2438
Tucson Community Hospice	(520) 230-4450
Valor Hospice Care	(520) 615-3996

Hospitals and Acute Care Hospitals

Cornerstone Hospital of Southeast Arizona	(520) 546-4595
HealthSouth Rehabilitation Institute of Tucson	(520) 322-4405
HealthSouth Rehabilitation Hospital of Southern AZ	(520) 742-2800
Heart and Vascular Institute (Carondelet Health Network)	(520) 696-2328
Kindred Hospital	(520) 584-4500
Northwest Medical Center	(520) 742-9000
Oro Valley Hospital	(520) 901-3500
St Joseph's Hospital (Carondelet Health Network)	(520) 873-3000
St Mary's Hospital (Carondelet Health Network)	(520) 873-3000
Tucson Medical Center	(520) 327-5461
UAMC South Campus	(520) 874-2000
University of Arizona Medical Center	(520) 694-0111
Southern Arizona VA Medical Center	(520) 792-1450

Housing

Rental Housing Search www.pimacountyhousingsearch.org

Active Adult Communities (Call PCOA for list)	(520) 790-7262
Adult Care Homes (Call PCOA for listings)	(520) 790-7262
Assisted Living Facilities (Call PCOA for list)	(520) 790-7262
Assisted Living Referral Agencies (Call PCOA for list)	(520) 790-7262
City of Tucson Public Housing	(520) 791-4616
Housing of Interest to Seniors (Call PCOA for list)	(520) 790-7262
Marshall Home for Men	(520) 624-5193
Mobile Home Parks (Call PCOA for list)	(520) 790-7262
Retirement Housing (Call PCOA for list)	(520) 790-7262
St Luke's Home	(520) 628-1512
Subsidized and Low-income Housing (Call PCOA for list)	(520) 790-7262
Transitional Housing (Old Pueblo Community Services)	(520) 445-7063

Moving Organizers

Caring Transitions	(520) 262-1495
ClutterSTOP	(520) 572-2244
Organizing Helpers	(520) 327-8586
Sharon Harn Organizing	(520) 360-1450
Solutions, Etc.	(520) 256-2121

Incontinence

Support and Resources

Incontinence Resource Center www.incontinencesupport.info

National Association for Continence	(800) 252-3337
The Simon Foundation for Continence	(800) 237-4666

Diapers for Low-income adults age 60 and over

Call Pima Council on Aging	(520) 790-7262

Diapers for Low-income adults under age 60

Pima County Health Department—South Office	(520) 889-9543
Pima County Health Department—East Office	(520) 298-3888
Pima County Health Department—North Office	(520) 243-2850
Pima County Health Department—Ajo Office	(520) 387-7206
Pima County Health Department—Green Valley Office	(520) 648-1626

Legal Services

Pima Council on Aging NAELA Clinic (Elder Law issues)	(520) 790-7262
Arizona Legal Document Association (ALDA)	(520) 338-2018
AZ Center for Disability Law	(520) 327-9547
Bankruptcy Court Help Line (Volunteer Lawyers)	(800) 556-9224
Family Law Free Legal Help	(520) 724-8456
Lawyer's Referral Service	(520) 623-4625
Notaries (Call PCOA for list)	(520) 790-7262
Southern Arizona Legal Aid	(520) 623-9465
Wills for the Greatest Generation (Call PCOA)	(520) 790-7262

Medical Clinics—Low Cost

Clinica Amistad	(520) 305-5107
Clinica del Alma	(520) 616-6760
Desert Senita Community Health (Ajo, AZ)	(520) 387-5651
East Side Health Center	(520) 574-1551
El Rio—Broadway	(520) 624-7750
El Rio—Congress	(520) 670-3909
El Rio—El Pueblo Health Center	(520) 573-0096
El Rio—Northwest	(520) 670-3909
El Rio—Pascua	(520) 879-6225
El Rio—Southeast	(520) 309-3210
El Rio—Southwest	(520) 670-3909
Flowing Wells Family Health Center	(520) 887-0800
Freedom Park Health Center	(520) 790-8500
Keeling Health Center	(520) 696-6969
Marana Health Center	(520) 682-4111
MHC Primary Care Health Center	(520) 616-4948
Pima Partnership Health Center	(520) 616-4944
Santa Catalina Health Center	(520) 825-6763
St Elizabeth's Health Center	(520) 628-7871
Tucson Clinica Medica Familiar	(520) 620-1200
United Community Health Center (Arivaca)	(520) 407-5500
United Community Health Center (Amado)	(520) 407-5510
United Community Health Center (Green Valley)	(520) 407-5400
United Community Health Center (Green Valley)	(520) 407-5900
United Community Health Center (Sahuarita)	(520) 576-5770
United Community Health Center (Three Points)	(520) 407-5700
University of Arizona Mobile Health Program	(520) 349-1624
University of Arizona Health Network	(520) 874-2000
University of Arizona Shubitz Family Clinic	(520) 393-9336
Van of Hope (Homeless Clinic)	(520) 240-6299
West Side Health Center	(520) 616-6790
Wilmot Family Health Center	(520) 616-6790

Medicare Information

Pima Council on Aging—SHIP	(520) 546-2011
Medicare	(800) 633-2273

Multiple Sclerosis (MS)

Banner Health Meds Connection	(602) 839-6733
Multiple Sclerosis Association of America (MSAA)	(800) 532-7667
Multiple Sclerosis Foundation	(888) 673-6287
National Multiple Sclerosis Society	(800) 344-4867

Muscular Dystrophy (MD)

Muscular Dystrophy Association	(800) 572-1717
UAMC MDA Clinic (South Campus)	(520) 874-2704

Nursing Homes and Acute Rehab Hospitals

Arizona Department of Health Services (Complaints)	(520) 628-6541
Avalon Southwest Health and Rehabilitation	(520) 294-0005
Carondelet Inpatient Rehabilitation (St Joseph's)	(520) 872-6279
Carondelet Inpatient Rehabilitation (St Mary's)	(520) 872-4340
Casas Adobes Post-Acute Care & Rehab	(520) 297-8311
Catalina Care Center	(520) 795-9574
Cornerstone Hospital of Southeast Arizona	(520) 546-4595
Devon Gables Healthcare Center	(520) 296-6181
Foothills Rehabilitation Center	(520) 733-8700
Handmaker Jewish Services for the Aging	(520) 881-2323
HCR ManorCare	(520) 299-7088
HealthSouth Rehabilitation Hospital of Southern Arizona	(520) 742-2800
HealthSouth Rehabilitation Institute of Tucson	(520) 322-4405
Kindred Hospital—Tucson	(520) 584-4500
Kindred Transitional Care & Rehab—Tucson	(520) 296-6100
La Cañada Care Center	(520) 797-1191
La Hacienda at La Posada	(520) 648-8388
La Rosa Healthcare	(520) 742-6242
Life Care Center of Tucson	(520) 575-0900
Mountain View Care Center	(520) 797-2600
Park Avenue Healthcare and Rehabilitation	(520) 882-6151
Pueblo Springs Rehabilitation Center	(520) 296-2306
Sabino Canyon Care Center	(520) 722-5515
Santa Rita Nursing and Rehabilitation Center	(520) 625-0178
Santa Rosa Care Center	(520) 795-1610
Sonora at Spendido	(520) 878-2600
The Forum at Tucson	(520) 325-4800
Villa Maria Care Center	(520) 323-9351
Ostomy Resources	
Ostomy Guide	www.ostomyguide.com
United Ostomy Associations of America, Inc	(800) 826-0826
Support Groups	(520) 206-0268

Parkinson's Disease Resources

American Parkinson's Disease Association	(800) 223-2732
American Parkinson's Disease Association—Arizona	(520) 326-5400

Banner Health Meds Connection	(866) 995-6432
National Parkinson Foundation	(800) 473-4363
National Parkinson Foundation—Arizona	(602) 618-7478
Parkinson Wellness Recovery (PWR GYM exercise)	(520) 591-5821
UAMC Movement Disorder Clinic (South Campus)	(520) 694-8888
Watermark at Home (In-home LSVT therapies)	(520) 886-4400

Planning for the Future

Partners in Planning (Call PCOA for information)	(520) 790-7262

Prescription Medication Help

Abbvie Patient Assistance Foundation (Abbvie meds only)	(800) 222-6885
American Kidney Fund	(800) 638-8299
American Organ Transplant Rx	(727) 526-0317
Astellas Patient Assistance Program (Astellas meds only)	(800) 477-6472
CancerCare® Co-Payment Assistance (3 cancer types only)	(866-552-6729
Chronic Disease Fund (Co-pays and travel expenses)	(877) 968-7233
ENcourage Foundation® (Enbrel only)	(800) 282-7752
Fosrenol On Track™ Support Program (Fosrenol only)	(866) 470-5858
Genentech® Transplant Access Services (Cellcept only)	(888) 754-7651
The HealthWell Foundation (Co-pay/deductible help)	(866) 316-7263
Leukemia & Lymphoma Society® (Co-pay help)	(877) 955-4572
Merck Patient Assistance Program (Merck meds only)	(800) 727-5400
National Osteoporosis Foundation Rx Discount Card	(800) 808-1213
Needy Meds (Search online for prescription help)	(800) 503-6897
Partnership for Prescription Assistance (Search for help)	(888)-477-2669
Patient Access Network Foundation	(866) 316-7263
Patient Advocate Foundation (Co-pay help)	(866) 512-3861
Patient Assistance Now (Novartis meds only)	(800) 245-5356
Pfizer Helpful Answers® (Pfizer meds only)	(866) 706-2400
Renassist® (Renvela and Hectorol only)	(800) 847-0069
Rx Assist (Search online for prescription help)	www.rxassist.org
Rx Hope (Search online for prescription help)	www.rxhope.com
The Safety Net Foundation (Amgen meds only)	(888) 762-6436
Shire Cares (Shire meds only)	(888) 227-3755
Walmart $4 Prescriptions Talk to your local Walmart Pharmacy	

Protective Services (Abuse and neglect)

Adult Protective Services	(877) 767-2385
Elder Shelter (Emergency Placement for Older Adults)	(520) 566-1919

Renal (Kidney) Failure

American Association of Kidney Patients	(800) 749-2257
American Kidney Fund	(800) 638-8299
Coalition for the Supportive Care of Kidney Patients (804) 320-0004	
Dialysis Patient Citizens	(888) 423-5002
Home Dialysis Central	(608) 833-8033
National Kidney Foundation Patient Hotline	(855) 653-2273
National Kidney Foundation Peer Support Line	(855) 653-7337

Respite

PCOA Respite Program (Call for screening)	(520) 790-7262
Casa Community Services (Green Valley)	(520) 625-2273
Community Services System Central Intake (PCOA)	(520) 790-7262
Handmaker's Adult Day Care	(520) 547-6037
Home Health Agencies (call PCOA for list)	(520) 792-7262
Interfaith Community Services (in-home volunteers)	(520) 297-6049
Lifespan Respite	(888) 737-7494
Senior Moments Adult Day Care (Vail)	(520) 561-0448
VA Medical Center (Facility Respite Program)	(520) 792-1450

Social Security Information

Social Security Administration	(866) 331-7693
Social Security Attorneys (call PCOA for list)	(520) 790-7262

Stroke and Aphasia Resources

National Aphasia Association	(800) 922-4622
National Stroke Association	(800) 787-6537
Saguaro Center for Speech & Language/Aphasia Center	(520) 730-8428
UAMC Clinic for Adult Communication Disorders	(520) 621-7070

Stoke Support Groups

Stroke Support—HealthSouth	(520) 322-3663
Stroke Support—HealthSouth	(520) 544-5240
Stroke Support—St Joesph's Hospital	(520) 218-5004
Stroke Support—St Joseph's Hospital (Aphasia)	(520) 873-3497
Stroke Support—St Joseph's Hospital (for caregivers)	(520) 873-3661
Stroke Support—Tanque Verde Lutheran Church	(520) 749-1606
Stroke Support—TMC	(520) 324-4345
Stroke Support—UAMC (Campbell)	(520) 626-2901

Suicide Prevention

PCOA safeTALK	(520) 790-7262
PCOA ASIST	(520) 790-7262
Survivors of Suicide	(520) 861-6632
Pasadera Behavioral Health Network	(520) 622-6000

Taxes

Federal and State Income Tax forms

IRS	(800) 829-1040
Arizona Department of Revenue	(602) 255-3381

Property Tax Exemptions, Refunds, and Freezes

Call PCOA for information and help	(520) 790-7262

Transportation

American Pony Express	(520) 888-2996
Arizona Medical Transit	(520) 792-0944
Arizona Senior Transport	(520) 573-6221
Cardinal Medical Transport	(520) 310-9855

Copper Star Transportation	(520) 312-0411
Crane Medical Transport	(520) 885-1733
DVA Transport Network for Veterans	(520) 792-1450
Friends In Deed (Green Valley and surrounding area)	(520) 625-4424
Interfaith Community Services	(520) 297-6049
ITN Greater Tucson	(520) 209-1645
Mike's Helping Hand	(520) 207-3917
Neighbors Care Alliance	(520) 790-0504
Pima Find-A-Ride	www.pimafindaride.org
Road to Recovery (for cancer patients)	(520) 321-7989 ext 3
Rural Transportation (Sun Shuttle)	(520) 792-9222
Sun Shuttle Dial-a-Ride (formally Handicar)	(520) 792-9222
Sun Shuttle Dial-a-Ride (Green Valley/Sahuarita	(520) 792-9222
Sun Shuttle Dial-a-Ride (Oro Valley/Catalina)	(520) 229-4990
Sun Tran	(520) 792-9222
Sun Van	(520) 798-1000
TRS Transportation	(520) 870-5306
Veterans Patient Travel	(520) 792-1450

Driving Assessments

Driving to Independence	(520) 219-0550

Driving Classes

AARP	(888) 227-7669

Utility Discounts

Assurance Wireless (Free Cell Phones and minutes)	(888) 321-5880
Q-Link Wireless (Free Cell Phones and minutes)	(855) 754-6543
Safelink Wireless® (Free Cell Phones and minutes)	(800) 723-3546
Southwest Gas	(877) 860-6020
Telephone Assistance Program	(520) 243-6730
Trash Discount	(520) 791-3171
Tucson Electric Power	(520) 623-7711
Tucson Water Zanjero Program	(520) 791-3242

Veterans Resources

Arizona Department of Veterans Services	(520) 207-4960
Old Pueblo Community Services	(520) 546-0122
Veterans Crisis Line	(800) 273-8255

Vision Resources

American Foundation for the Blind	(800) 232-5463
Braille and Talking Book Library (AZ only)	(800) 255-5578
Desert Low Vision Services	(520) 881-3439
EyeCare America's Senior EyeCare Program	(877) 887-6327
Foundation for Fighting Blindness	(800) 683-5555
iCanConnect	(520) 792-1906
Lions Sight and Hearing Foundation	(800) 246-9771
National Federation of the Blind in Arizona	(520) 733-5670

New Eyes for the Needy (Call PCOA)	(520) 790-7262
SAAVI	(520) 795-1331
Sun Sounds	(520) 296-2400
Tucson Society of the Blind	(520) 886-1913

Volunteer Opportunities

Catalina Community Services (Catalina area)	(520) 825-0009
Interfaith Community Services	(520) 297-6049
Marana Health Center/Arizona Lions Club	(520) 682-4111
Neighbors Care Alliance (through Pima Council on Aging)	(520) 790-7262
Valley Assistance Services (Green Valley)	(520) 625-5966
Pima Council on Aging Volunteer Program	(520) 546-2002
TMC Senior Services	(520) 324-1960
Volunteer Southern Arizona	(520) 881-3300

For more information regarding senior services and resources, please call the Pima Council on **Aging Help Line: .... (520) 790-7262 or email help@pcoaorg**

This guide attempts to list the most commonly requested services, but it is not all-inclusive. The information listed is updated periodically and may not be current Pima Council on Aging assumes no responsibility by providing this information. This guide is a community service and not an endorsement of any organization listed.

Additional underwriting provided by

Sunrise at River Road
4975 N. 1st Ave.
Tucson, AZ 85718
520-888-8400

Caregiver Services

For caregivers and their families

Individual and Family Consultation

- In person or on the phone
- Accurate information about community resources and public benefits
- Strategies for reducing caregiver stress and improving family communication
- Assistance in planning ahead

Family Caregiver Support Groups

Family caregiver support groups are available in several locations throughout Pima County and open to anyone providing care for a person age 60 and older, or for someone who has Alzheimer's disease or a related dementia of any age.

Respite Services

Respite care may be provided for a few hours weekly in the home or through a temporary stay in a facility. Respite is provided on a cost-sharing basis determined by income and ability to pay. To qualify for respite, the caregiver must live with the care recipient.

Family Caregiver Training

PCOA contracts for family caregiver training that is offered in two parts: a four-hour classroom learning experience and a four-hour hands-on workshop.
For further information please contact: Luminaria Home Care at (520) 488-7340.

Grandparents Raising Grandchildren

PCOA contracts for services for grandparents raising their grandchildren. The Kinship, Adoption Resource and Education (KARE) Family Center provides a wide range of services through its one-stop center. For more information please call (520) 323-4476.

For more information, please call PCOA's Helpline at (520) 790-7262.

Caregiver Services

A program of Pima Council on Aging
Area Agency on Aging, Region II (Pima County)

PCOA
PIMA COUNCIL ON AGING
Advocacy, Action, Assistance

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