Section 11
Legal and Financial Issues
Where to Find My Important Papers

By Family Caregiver Alliance

Name: ___________________________ Social Security #: ______________
Spouse/Partner name: ______________ Social Security #: ______________
Address: __________________________________________________________________
Date prepared: ________________ Copies given to: ______________________________

My valuable papers are stored in these LOCATIONS (address or where to look):

A: Residence: ____________________________
B: Safe Deposit Box: ____________________________
C: Other: ________________________________

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Retirement accounts (IRA, 401K, etc.)                 |  □       |   □      |   □      |
Funeral arrangements                                  |  □       |   □      |   □      |
Titles and deeds                                      |  □       |   □      |   □      |
Notes (mortgages)                                     |  □       |   □      |   □      |
List of stored and loaned items                      |  □       |   □      |   □      |
Auto ownership records                               |  □       |   □      |   □      |
Birth certificate                                     |  □       |   □      |   □      |
Military/veteran’s papers                            |  □       |   □      |   □      |
Marriage certificate                                  |  □       |   □      |   □      |
Children’s birth certificates                         |  □       |   □      |   □      |
Divorce/separation records                           |  □       |   □      |   □      |
Passwords (important websites, banking, credit card, social media, computer, wi-fi, phone, etc.) |  □       |   □      |   □      |
Safe deposit box key                                  |  □       |   □      |   □      |
Other _____________________________________________ |  □       |   □      |   □      |

Emergency contact: ___________________________________________________________

Doctor(s): _________________________________________________________________

Clergy: ________________________________________________________________

Attorney: __________________________________________________________

Accountant: ____________________________

Insurance agent/policy #(s): ____________________________

Other contacts: ______________________________________________________

Modified with permission of Passages Caregiver Resource Center (formerly Mountain Caregiver Resource Center).
Family Caregiver Alliance and Passages CRC are part of California’s statewide system of Caregiver Resource Centers.

Rev: 170807
Definitions of Legal Documents

By Pima Council on Aging

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.

Legal Planning for Incapacity

By Family Caregiver Alliance.
(Note: Modified with Arizona-specific information)

As you face aging and the need to make plans for your future, you face having to make legal decisions about many aspects of your lives. These legal decisions not only protect you from others doing things you might not like to you, they also protect family and loved ones by giving them guidance in the care that you would like to receive. After completing all the legal paperwork, the next step is to sit down and talk to family about the decisions you have made and why.

What Life Care Planning Documents Everyone Should Have?

Advance Health Care Directive
- Gives power to a person you designate to make health care decisions for you ONLY IF you can’t speak for yourself
- Also called Living Will, Durable Power of Attorney for Healthcare
- Each state has slightly different versions of the form, but a form from one state will be honored in another state
- Hospitals and doctor’s offices have the forms
- Everyone over 18 should have one
- Must be completed while you are competent to know what you are signing, i.e. without dementia
- Often used to decide on feeding tubes, ventilators, and other treatments at the end of life or when someone is unconscious
- Only needs to be witnessed; does not need to be notarized

What happens if you don’t have an Advance Health Care Directive?
- Doctors will do everything to treat your condition and keep you alive
- Family will be asked what to do
- If they don’t know what your wishes would be, there might be family conflict and guilt over making the wrong decision
- Physician training, hospital, and nursing home policies often dictate the use of “heroic means” to sustain life. For example, “reviving” a very ill person after a stroke, and using a respirator for someone deemed medically “brain dead,” are standard procedures in many hospitals.

Arizona: Prehospital Medical Care Directive (PMCD)
- This Orange colored form is a document signed by you and your doctor that informs emergency medical technicians (EMTs) or hospital emergency personnel not to resuscitate you. Sometimes this is called a (DNR) Do Not Resuscitate. If you have this form, EMTs and other emergency personnel will not use equipment,
drugs, or devices to restart your heart or breathing, but they will not withhold medical interventions that are necessary to provide comfort care or to alleviate pain.

- Since it is a physician’s order, it is not open to the will of others.
- IMPORTANT: Under Arizona law a Prehospital Medical Care Directive must be on letter sized paper or wallet sized paper on an orange background to be valid.

What happens if you don’t have a Prehospital Medical Care Directive (PMCD)?
- If 911 is called, EMTs are required to do everything possible to resuscitate a person and keep him/her alive until they arrive at the hospital.

Will
Says how you want your estate (money and belongings) to be dispersed to family, friends, organizations, etc. after you die.

- Also called Last Will and Testament
- Each state has different laws about estates, but most states will honor an out-of-state will
- Can be hand written or completed using on line forms, but necessary to be witnessed and/or notarized
- If estate is complicated or over $100,000, it is best to have an attorney help you write the will or review what you wrote
- Must be completed while you are competent to know what you are signing, i.e. without dementia
- In a will, you appoint someone to be the executor or administrator who will pay your final bills and see that your wishes are carried out
- Probate is the transferring of property when someone dies. The probate court oversees the executor to assure that the estate is divided as stated in the will.

What happens if you don’t have a will?
- If you die without a will, the court will probate your estate, i.e., decide how your estate should be distributed.

Durable Power of Attorney for Finance
Allows someone to access your finances, including checking account, investments, and property, in order to pay your bills.

- A Durable Power of Attorney is valid even if you are incapacitated.
- Must be completed while you are competent to know what you are signing, i.e. without dementia.
- Needs to be someone you trust, as this person has a lot of control over your finances. If you don’t have someone you trust, you should consult a professional.
- Spouses might not have access to all of your funds unless everything, including investments, is held as joint property.
What happens if you don’t have a Power of Attorney for Finance?

- If you don’t have a durable power of attorney for finance and you can’t manage your finances, a judge will have to appoint someone to do so. It may mean you will have to be conserved, e.g. someone appointed by the court will oversee your care and finances.

Final Arrangements

- Decide whether you would like cremation or burial and let the family know. Also let loved ones know about your wishes regarding organ donation and other special arrangements.
- Put your wishes in writing in a place family members can find them.
- The more decisions you make beforehand, the fewer decisions family has to make during a difficult time when they are grieving.

What happens if you don’t make your wishes known about final arrangements?

- Family can often be in conflict about what you would have wanted.
- The law can determine who has the power to make the decision if it is unclear or there is conflict.

What Are the Other Things You Might Need?

Trusts

A trust creates a legal entity that holds your assets for you so that your estate does not have to go through probate when you die.

- Also called a Living Trust
- You name a trustee to oversee the trust both while you are alive, and to distribute the trust to beneficiaries when you die.
- You may be the trustee of the trust while you are alive, in which case you name a successor trustee for the trust who will manage it after you die or become incapacitated.
- A revocable trust allows you to control everything that happens in the trust while you are alive.
- An irrevocable trust cannot be changed without the beneficiary’s consent.
- There are many options for trusts for specific purposes, such as:
  - Special Needs Trusts: Puts money aside to help someone who is disabled
  - Charitable Trust: Money given to a charity
  - Bypass Trust: Irrevocable trust passes assets to the spouse and then the children at death of second parent, limiting estate taxes
  - Life Insurance Trust: Removes life insurance from estate and thus estate taxes
  - Generation Skipping Trust: Allows grandchildren to directly inherit without paying taxes
What happens if you don’t have a trust?
- Depending on the value of your assets, your estate will go through probate, which can take several months and incur costs to the court.

Beneficiary Forms
Bank accounts, investments, insurance, and retirement plans can be designated as “payable on death” to a named beneficiary, which means the funds don’t have to go through probate.
- Allows access to funds immediately, rather than waiting for probate to close

What happens if you don’t have fund “payable on death?”
- Unless funds are in a trust, the estate must be probated through the court, which can take several months (when the funds might not be available) and incur costs to the court.

Where to Find My Important Papers
Have a central place to keep wills, trusts, powers of attorney, etc so that family members will know where to look for these documents. Please see attached form: Where to Find My Important Papers (Section 11.)

Where do I get these forms?
Life Care Planning Packet: Life Care planning packets contain the following useful documents and directions for completing them: Durable Medical Health Power of Attorney; Durable Mental Health Power of Attorney; Living Will; Letter to my representative for health care decisions; Pre-hospital Medical Care Directive (Do not resuscitate); and, Registration form for state data base. A list of elder law attorneys is also available who can help with life planning. Call PCOA at (520-790-7262) to receive these life care planning resources. Life care planning packets can also be downloaded and more information obtained by visiting the Arizona Attorney General’s website: www.azag.gov/seniors/life-care-planning.

What Every Caregiver Needs to Know About Money

By Family Caregiver Alliance

Every family has unspoken rules and expectations about how they deal with money: how to save, how to spend, who has control, how decisions are made. When you become a caregiver for someone, money plays an important part in the choices you make about their care. And without question, money can be a huge source of friction within the family.

Many older people were raised during the Depression or had parents who shared a “Depression mentality.” Saving was important. Having money for a “rainy day” was essential. Not wasting was important. Anxiety about running out of money was an issue. A nest egg that allowed parents to leave an inheritance to their children was a matter of pride. And many adult children expect to receive an inheritance and want to maximize the amount they will receive.

Once a person needs a caregiver, money has to be discussed. Many older adults are reluctant to let their adult children know about their financial situation. It’s hard to admit that this is the “rainy day” they have been saving for all their lives. Understandably, they are extremely reluctant to give up control of their finances. However—and particularly when someone shows evidence of cognitive decline—a caregiver has to oversee the finances to prevent mistakes—bills not paid, or paid more than once, investments not looked after, irrational spending, or just losing money in the house or on the street.

Talking About Money

Without a clear grasp of the financial situation of the person needing care, the caregiver will be hampered in his/her ability to make good long-term financial decisions. Starting the conversation can be the hardest part. Should you have the conversation one-on-one, or should it be a family meeting with siblings and other important people present? Maybe this conversation sounds familiar to you:

“Mom, we’re going to have to make some difficult decisions in the next few years. It would help if we could work together to understand the finances so we can make the best decisions for your care as your needs change.”

“Oh, dear, I don’t want to talk about that now. Things are fine and I’m handling all the bills without any problems.”

“I know things are good now, but what if you fell and broke your arm and couldn’t write a check? Then how would your bills get paid?”

This is a time to start the “what if” conversation. Suggest likely scenarios and ask “what would you want if …” and write down your parent’s responses. Some of these can be about health care wishes or living arrangements, and some of these will be about money. The better you understand how your loved one thinks about money, as well as what
his/her concrete wishes are, the better you’ll be able to carry out those wishes and feel good honoring them to the best of your ability.

This leads to a conversation about other aspects of aging that involve money:

- Is the home the best place for the care receiver to be?
- Is it more expensive to pay for assisted living, or is it more expensive to hire a caregiver at home?
- If I, as an adult child, provide the care, can I spend some of my parent’s money on hiring substitute or respite help so I can get a break from time to time?
- Would it be better for my parents to pay me to be the caregiver, or is it better to hire from outside?
- If we want to hire someone, should it be through an agency or should we hire privately?

Financial Aspects of Becoming a Caregiver

By Family Caregiver Alliance

Questions to ask yourself and other family members:

- How will my rent/mortgage be paid if I move in with Mom or Dad?
- Are family members okay with having Mom/Dad reimburse me for the added expenses I will accrue in taking care of them? These might include living expenses, medical expenses, transportation, and food.
- If I am providing the primary care, will you (other family members) be able to help, or will I be expected to do it all? How can we divide up the responsibilities? If I am getting paid, should you get paid for the things you do?
- How will we, as a family, make decisions about Mom’s/Dad’s care? How do we decide how their money will be spent? Who will be in control of the finances?
- Where will I go for support? Will my friends or family help me get breaks? What hobbies or other things do I have that will engage me in my down time as a caregiver? How will I have the spending money to be able to go out with friends or buy things I want?
- If I am the primary caregiver, are you okay with my spending Mom’s/Dad’s money to help care for me, too? This will mean there might be less available in the inheritance. Should I get a different percentage of the inheritance if I have done all the work? If I don’t quit my job and do this, are you okay with hiring help to care for Mom/Dad? This, too, will affect your inheritance.
- If Mom or Dad needs to move into an assisted living community or nursing home, how will we make that decision, and how much will finances play a part in the decision-making?
- If Mom or Dad does run out of money, can any of us help pay their living expenses?
- What do we need to know about Medicaid and Medicare coverage to make good decisions about paying for care in the future?

Money Is an Emotional Issue

By Family Caregiver Alliance

We all have emotional triggers when we talk about money. Is money equivalent to love? Does someone get more money because of need or because he or she is the “favorite”? Have the parents provided support for one sibling all these years? What will happen to him or her when parents are no longer able to help?

If a parent won’t let the family caregivers oversee finances, there can be feelings of not being trusted or being treated like a child. Should an inheritance be divided equally or given to whoever needs it most, or to whoever did the most work? If there is not a lot of money, there can be feelings of anger and resentment over the feeling that the parents put the adult children in a difficult situation. If there is a lot of money, greed can become a motivating factor in making decisions.

Often families divide up who is handling the money and who is doing the caregiving. This puts the caregiver in the position of having to ask for money, and the person handling the money has control over how money is spent. This can lead to tension and family estrangement.

Frequent Comments and Questions

- “If only my parents had been more frugal.”
- “I have always been the responsible one, and now you’re getting the same amount of the inheritance as I am.”
- “Dad was so irresponsible, he didn’t plan for old age or illness and now I have to figure everything out.”
- “How do I respect Mom’s wish not to be in a nursing home when she has no money to hire extra help at home?”
- “If I move Dad in with us, can we charge rent to offset the added expenses? How will my siblings feel if we do this?”
- “How can I get Mom to spend her money on her care now, rather than thinking she needs to keep saving it for the future?”
- “Shouldn’t my wealthy sister pay more for Mom’s care than I do, since I don’t have as much?”
- “Can Mom and Dad gift us money now so they will qualify for a nursing home under Medicaid later? Can I trust you to not spend the money so it will be there if Mom and Dad need it in the future?”
- “Will you send us all the bank statements since you are overseeing their finances? We want to know where their money is going.”
- “I need a break from caregiving. Will you use some of their money to pay for someone to look after Mom for a weekend so I can get away?”
• “We are paying for a caregiver to be with Dad three days a week. Will you do a shift on one of the other days? If not, will you pay more to cover the caregiver’s costs?”
• “Mom had an investment worth $100,000. What happened to it?”

When Dementia Is a Factor
If the care receiver does not have dementia, he or she has the right to make decisions, including bad decisions. This means he/she can make seemingly irrational decisions about money and how to spend it or not spend it. This is very hard for caregivers to accept—we want to help do things “right” and make logical decisions. Also, we worry that we will have to pick up the pieces and solve problems that arise if money is not handled judiciously. Each family struggles with this in their own way. Bringing in an outside person, such as a minister, attorney, social worker, or physician might help.

Whether someone has dementia or not, elders can be subject to “undue influence.” People who befriend them may find a way into their hearts—and pocketbooks—in ways that can lead to the older person being “overly generous” with his or her funds. Keeping an eye on the finances can help you catch any extraordinary outflows of money.

If Mom or Dad does have dementia from a disorder such as Alzheimer’s disease, stroke, or another condition, they need more oversight to make sure the finances are handled appropriately. Help is needed now, because making logical, rational, and reasonable decisions might not be possible later. And since dementia gets worse with time, processes need to be put in place as soon as possible, so that someone can handle the finances down the road. It is easier to do this while the care receiver is still able to understand and sign the necessary documents to give the caregiver or a fiduciary the necessary powers. If it is not done in a timely manner, it may be necessary to apply for a conservatorship, which is expensive, emotionally wrenching, and time-consuming. If legal planning has not been done, start with an estate planning or “elder law” attorney who can help with writing a will or trust, and also complete Power of Attorney for Finances, which can be activated when the time is right. For a list of Elder Law Attorneys, contact PCOA (520) 790-7262.

Money, Money, Money: It’s Always About the Money
Many family fights and tensions are centered on the issues of money—who has it; who doesn’t; how it is spent; how it is decided how it’s spent; what the family’s past issues were around money; what the issues are now. It is challenging to deal with the complexity of our emotions about parents, illness, aging, and death, and sometimes these emotions come out in conflicts about money. Holding a family meeting with a facilitator might help the family come together rather than be torn apart by these issues.

Work and Eldercare

By Family Caregiver Alliance

As an adult child caring for an aging parent, you are probably torn in many directions. You have a job with responsibilities and expectations. You may have a spouse and children to provide for. And you need to take care of yourself. Taking care of yourself is supposed to include exercise, eating right, socializing with friends, and having down time. Somewhere in there you’re supposed to sleep. Now add caregiving to the mix and handling the finances for someone else. Balancing all of this becomes one more thing you have to do. It’s easy to become overwhelmed.

Many caregivers contemplate leaving their job so as to be more present and available to someone who now needs help on a daily basis. This is a complex decision to make, as it affects not only your finances (and your family’s), but also the finances of your parent and maybe even your siblings or other extended family members. When you stop working, you immediately have to deal with changes in health insurance. Under COBRA you can pay privately for insurance for 18 months, or, under the current Affordable Care Act, you can buy health insurance on the open market (without penalty for pre-existing conditions). But this will cost money for you or for the family member you are responsible for.

Taking care of someone in the here and now is important, but planning for your own aging is also important. Not having a current income will compromise your income in the future. If you don’t pay into the Social Security system for a number of years, your income will be reduced when it comes time for you to collect your Social Security benefits. Pensions, retirement funds, IRAs, 401K employer matches, and other savings accounts can be similarly affected. Leaving a job may affect future job advancement, which will also affect later earnings. And work may also serve as your outlet, diversion, and social support.

What Employers Can Do

Caregiving as a workplace issue is now recognized by a growing number of employers. Larger corporations are sometimes able to offer support in ways small ones cannot, but there are actions that companies of any size can take to support employees who have caregiving responsibilities:

- The most requested work adjustment is flexibility in work hours. This may include allowing a shift in schedules (e.g., working 10:00 a.m. to 6:00 p.m. instead of 9 to 5; a compressed work schedule (four ten-hour days instead of five eight-hour days); a part-time schedule; job sharing; or telecommuting. A limit on mandatory overtime is also helpful. Studies have shown that flexible scheduling improves job performance, decreases tardiness and employee turnover, and increases job satisfaction and retention (even for employees who are not currently caregiving).
• Human Resources or Employee Assistance Program staff can provide information on helpful Internet sites, local community services, care managers or resource centers, and should provide information about leave programs and other company policies.

• Training for supervisors enhances understanding of the conflicting demands of work and caregiving and ensures that mandates for family leave and antidiscrimination regulations are met.

• Various state regulations and certain sections of the ADA (Americans with Disabilities Act) prohibit employers from discriminating against caregiving employees (for example, passing over employees for promotion, stereotyping employees because of caregiving status).

• Companies with 50 or more employees must comply with the federal Family and Medical Leave Act (FMLA), which allows for up to 12 weeks of unpaid leave (or 26 weeks to care for an active service member). The leave may be used to care for a seriously ill parent, spouse, or child. Job and health insurance are protected. However, approximately half of US companies have fewer than 50 employees and therefore are exempt from FMLA requirements. Nonetheless, many use FMLA guidelines to provide support for individual employees.

• Paid Family Leave (PFL) is a mandated benefit that covers caregivers of a seriously ill parent, child, spouse, or registered domestic partner, as well as new parents. California and only a handful of other states currently offer paid family leave. In California, employees may receive up to 55% of their wages for six weeks of leave. Job security is not protected. Workers who already pay in to the existing State Disability Insurance (SDI) system (you will see it as a deduction on your paycheck) are eligible for paid family leave.

• Some larger employers offer "cafeteria-style" employee benefits, which allow employees to select supplemental dependent care coverage to partially reimburse costs for in-home care or adult day care. A few companies offer subsidized payments for geriatric care managers.

• Sometimes larger businesses organize in-house caregiver support groups, informational "brown-bag" lunch sessions, or coordinate with local community groups or hospitals so that employees can attend an outside support group.

• Some employers arrange group purchase of long-term care insurance for employees, spouses, and dependents.

• Other supportive, low-cost things employers can do include publicizing a telephone hotline for caregivers, and publishing a list of key contacts or advice in the employee newsletter.

How Can I Be Paid to Be a Caregiver to My Parent?

By Family Caregiver Alliance

(Note: Modified with Arizona-specific information)

One of the most frequent questions asked at Family Caregiver Alliance is, “How can I be paid to be a caregiver to my parent?” If you are going to be the primary caregiver, is there a way that your parent or the care receiver can pay you for the help you provide? The short answer is yes, as long as all parties agree. If the care receiver is eligible for Medicaid called, Arizona Long Term Care System (ALTCS). It might be possible for you to be paid through In-Home Supportive Services (IHSS). To learn more, call ALTCS at (520) 205-8600 or PCOA at (520) 790-7262. The next article shares how to develop a Personal Care Agreement for when a family member is paid by family to care for a loved one.

Note: Modified with Arizona specific information.
Personal Care Agreements

By Family Caregiver Alliance

How to Compensate a Family Member for Providing Care: Introduction

Many families reach a point when they recognize that an ill or older relative needs help. There are usually warning signs: difficulty with daily activities; memory problems; trouble with banking and finances; multiple falls; problems with driving; forgetting medications. Sometimes an elderly or ill loved one needs more than occasional assistance — they need full-time care.

But who will provide that care? The answer is usually close to home: an adult child. One sibling might become the caregiver by default, or one is selected because he or she lives closer or has fewer family responsibilities of his/her own.

The person providing care for a loved one may make a significant sacrifice: giving up a job and employment benefits. A formal agreement among family members can provide a way to compensate a person providing care if he or she is no longer able to hold other employment. Even though most family members want to help and feel a sense of duty to care for a loved one, it is a job with heavy time commitments and responsibilities. One way of protecting the caregiver as well as the person receiving care is by putting the care relationship in writing.

This is a binding agreement, also called a long-term care personal support services agreement, elder care contract, or family care or caregiver contract. Most often, it is called a personal care agreement. This agreement can offer family caregivers security that they will not suffer undue financial consequences. At the same time, the agreement can also offer your loved one peace of mind that she or he has a caring advocate to manage care needs.

What Is a Personal Care Agreement?

The agreement is a contract typically between a family member who agrees to provide caregiver services for a disabled or aging relative and the person receiving care. The personal care agreement is most commonly between an adult child or and his/her parent, but other relatives may be involved, such as an adult grandchild caring for a grandparent.

Drawing up an agreement clarifies for a family what tasks are expected in return for a stated compensation. It can help avoid family conflicts about who will provide care and how much money will change hands. For this reason, the agreement should be discussed with other family members to resolve any concerns before an agreement is drafted.

When contracting with a family member, it is wise to treat the agreement as a legal document. If your relative is receiving state supported in-home care, the agreement will show the state where the money is going and for what kind of services. In addition, a caregiver agreement can offset potential confusion among family members concerned about bequests to heirs, and avoid misunderstandings later over the reduction of the amount of money that may be inherited.
Basic Components of a Personal Care Agreement

A personal care agreement has three basic requirements for a person to pay a family member for care:

• The agreement must be in writing.
• The payment must be for care provided in the future (not for services already performed).
• Compensation for care must be reasonable. This means it should not be more than what would be paid to a third party for the same care in your state or geographic area. Tasks performed should match “reasonable” or “customary” fees typically charged for those services.

A properly drafted personal care agreement will contain:

• Date the care begins
• Detailed description of services to be provided, for example, transportation and errands: driving to medical, dental, adult day care, and other appointments, food preparation
• How often services will be provided (Allow for flexibility in care needs by using language such as, “no less than 20 hours a week” or “up to 80 hours a month.”)
• How much and when the caregiver will be compensated (weekly or biweekly)
• How long the agreement is to be in effect (The agreement should set time, such as a year or two years, or even over a person’s lifetime.)
• A statement that the terms of the agreement can be modified only by mutual agreement of the parties in writing
• The location where services are to be provided (home of elder/adult with disabilities, home of the caregiver, other location. Allow for the location of the care to change in response to increasing care receiver needs.)
• Signatures by the parties, date of the agreement

Additional Details to Consider in an Agreement

The caregiver’s tasks should be clearly stated in the agreement but might include the term “or similar to be mutually agreed upon by the parties” for flexibility. If the agreement is too rigid, it will have to be rewritten if circumstances change.

Consider creating an “escape clause” in the event that one of the parties wants to terminate the contract. Use a term such as “this agreement remains in effect until terminated in writing by either party.” Consider a provision that “springs” into action if the caregiver becomes ill or wants a vacation. Is there a designated backup person who can step in temporarily?

Is there a provision for room and board costs if the care recipient lives with the caregiver (a proportional share of utilities, mortgage, insurance, taxes)? Consider what happens if the care recipient moves into a care facility. Will health insurance or a long-term care insurance policy be purchased to cover the family caregiver? If so, include that in the
personal care agreement and be specific without being inflexible. Consider adding an allowance for easy-to-overlook out-of-pocket expenses.

To determine the level of care required, consult with a local homecare agency, physician, geriatric care manager, hospital discharge planner, or social worker. There may be a fee involved to conduct a care assessment in the home. This will also help in anticipating any future care needs. If the care receiver has dementia, for example, a decline could require different care options.

Examples of care are: personal care, grocery shopping, preparing meals, housekeeping, laundry, coordinating household and medical bills, making phone calls, financial management, transportation (consider mileage), monitoring and managing medications, tracking changes in health, and liaison with healthcare practitioners.

When preparing an agreement, ask yourself what each care task means. Define, for example, what “personal care” is: does it include bathing, dressing, and dental hygiene? If you specifically define the care tasks and the time required, the result will be a more realistic caregiving assessment.

Caregivers should maintain a detailed daily log and have a concise job description. Documentation will support the intent of your contractual relationship if for any reason it comes into question.

You are creating a contractual relationship between employer (care recipient) and employee (caregiver), a relationship that requires withholding and paying taxes. Other considerations are whether to provide employee benefits such as health insurance or workers’ compensation. In the area of taxes and Social Security, you may want to seek the advice of an attorney to confirm what applies in your situation. Consider a vacation pay provision to offset caregiver stress or a raise after one year for a job well done.

**How to Discuss Personal Care Agreements Within the Family**

A stressful conversation for any family is what happens to the money when a parent becomes ill, and who will serve as the primary caregiver. One method for discussing difficult topics is holding a family meeting. The caregiving team meets in a comfortable place, seated around a table with room to spread out documents under discussion. (Using technology such as Skype may help to include family members who live far away.) A well-organized meeting can provide the family members with shared support and a better understanding of the decisions to be made.

When planning the family meeting, it is important to include all necessary members. One question to consider is whether the person receiving care will attend. If your loved one has a cognitive condition (Alzheimer’s Disease or another dementia, for instance), consider whether or not he or she has the capacity to understand the discussion and whether the topic is likely to be upsetting. Are there “hot-button” issues not to be discussed in their presence? How critical is it for them to participate in decisions made on their behalf? Attending all or part of the meeting may allow the care receiver to build trust in the caregiving team. This can help later with their cooperation when tougher decisions must be made.
Before the meeting, it is best to set times and dates convenient (as much as possible) for everyone’s schedule, then create your meeting agenda.

**Here is a suggested list of topics to keep the discussion on track:**

- Define the role of the caregiver, with tasks clearly delineated
- The duration of the agreement
- Compensation for caregiving, including how it will be paid (weekly, monthly, lump sum?)
- Financial changes to the family estate (present and future impact)
- Who holds Power of Attorney?
- Who will serve as a backup should the caregiver become sick or need respite?
- Are there Medicaid “spend down” or “look back” period considerations?
- Is there a Health Care Directive?
- Is a physician on the team?
- How does the care receiver perceive his/her quality of life and independence? (What are their wishes?)
- What is the plan if it becomes time for placement in a residential facility?

If possible, record your meeting or have someone take notes. You might distribute meeting notes to other family members for future reference. Consider building a “personal care agreement” binder that contains necessary documentation. One person should facilitate the meeting to keep the discussion moving or to set boundaries if the discussion gets out of hand. Some families choose to use an outside facilitator, a social worker, clergy member, geriatric care manager, or another person without a vested interest in the meeting outcomes. More than one meeting may be necessary.

**Below are a few examples of documents that may be helpful:**

- Documentation showing the median hourly compensation for a caregiver in your area. (Call local home care agencies to get a sense of costs.)
- Medical records relevant to caregiver tasks
- The completed care assessment documenting level of care
- Additional legal documents such as Health Care Directive, Power of Attorney
- Financial documents and will and trust agreements

Should the meetings not reach desired goals, family mediation is a growing trend in the U.S., helping families deal with major life transitions. For more information, see the National Care Planning Council noted in the Resources section at the end of this fact sheet.

**Do I Need a Lawyer?**

You don’t necessarily need to hire an attorney, but it may be advisable when entering into a contractual relationship. It depends on your set of circumstances and how complex an agreement your family requires. If you are considering a pre-paid, lump-sum caregiver contract, you may want to consult with a lawyer. A lump-sum contract is complex, and it’s
more difficult to show compensation in terms of "fair market" value for care services. A monthly or bi-weekly salary for care services is easier to track, especially for Medicaid purposes. If you are not comfortable with these transactions, consult an attorney to avoid conflict later.

Another legal consideration is if the care receiver lacks capacity to sign the agreement. The person holding the Power of Attorney or the guardian or conservator may sign. If the family caregiver also holds the care receiver's Power of Attorney or legal guardianship, consider consulting with an attorney. If you feel there is no need for an attorney, see examples of agreements in the Resources section.

**How Does This Affect Eligibility for Medicaid?**

Medicaid (ALTCS) is a state and federal program that may pay for long-term care costs for people with limited income and assets. To qualify for Medicaid, the spending and assets of an individual are subject to a “look-back” period of up to five years. This is sometimes called the asset “spend down.” If the care receiver needs to enter a facility or apply for other services that Medicaid might pay for, the personal care agreement can show that care payments were a legitimate expense and not an attempt to hide assets by giving cash to family members. The care receiver is paying for the “value” in personal care services.

Check your state for Medicaid, rules since regulations do vary from state to state. These regulations are complicated, and you may want to consult an elder law attorney for help in qualifying for Medicaid-ALTCS.

*Source: Family Caregiver Alliance, Personal Care Arrangements, www.caregiver.org.*
Elder Abuse, Neglect and Exploitation

By the Arizona Department of Economic Security, Adult Protective Services

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. Emotional abuse is in statute but not APS statute.

**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 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)

Effective November 1, 2017, APS will no longer accept fax, mail, or walk-in reports of abuse, neglect, or exploitation of vulnerable adults. APS will continue to accept phone reports Monday - Friday 7:00 a.m. to 7:00 p.m. and Saturday, Sunday and state holidays 10:00 a.m. to 6:00 p.m. (1-877-SOS-ADULT /1-877-767-2385). Online reports are available 24 hours a day, seven days a week at www.azdes.gov/reportadultabuse.

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
If you’ve been reading about wills or trusts you have most likely come across the term probate. Clearly, this is a central issue in estate planning, but what exactly is probate?

Probate is a legal process that finalizes an individual’s personal affairs after his or her death. It includes:

- Proving to the court that the individual’s will is valid
- Identifying and inventorying the deceased person’s property
- Conducting a property appraisal
- Paying any debts or taxes owed by the individual
- Distributing the individual’s property according to the provisions set forth in his or her will

The executor—or an attorney and the executor—can handle the paperwork and court appearances included in probate. Most individuals choose the latter, as probate attorneys can make the entire process much simpler. Probate attorneys can be expensive, however, because they often charge a large percentage of the overall estate as their fee. If you wish to avoid these additional estate costs, try to find an attorney who will agree to work with you for less than the normal fee, or find a general executor’s handbook that helps the executor complete the process without an attorney.

Generally, the probate process occurs as follows:

- The executor (if the deceased had a will) or court-appointed representative (if the deceased did not have a will) files papers with the probate court.
- The individual proves the validity of the will and gives the court a list of the deceased’s property, debts, and estate.
- Relatives and creditors are officially notified of the death.
- During the year it takes for probate to conclude, the executor or representative must find and manage the deceased’s assets.

Luckily, there is some property that passes through probate, including a simple transfer of property to a surviving spouse, and any property held in joint tenancy or a living trust. Because the probate process is time-consuming, expensive, and usually unnecessary, many individuals choose to avoid probate altogether by leaving their property in the form of trusts rather than wills. An individual who has a significant amount of property, or who does not wish his or her estate to become public record, should look into creating a trust to avoid probate. Sometimes probate can be beneficial, however, such as in the case of family members who don’t get along or when the deceased has outstanding debts that can’t be easily paid.

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