

What Every Caregiver Needs to Know About Money

By Family Caregiver Alliance and reviewed by Harrison Lazarus, CPA.

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Introduction

It sometimes seems that people are more comfortable talking about sex than money. 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?

Work and Eldercare

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. (For more information on juggling caregiving and your job, see the FCA fact sheet [Work and Eldercare](#).)

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 effect later earnings. And work may also serve as your outlet, diversion, and social support.

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. (To learn how to set up a formal arrangement for payment, see the FCA fact sheet [Personal Care Agreements](#).) If the care receiver is eligible for Medicaid (MediCal in California), it might be possible for you to be paid through In-Home Supportive Services (IHSS).

Financial Aspects of Becoming a Caregiver

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 effect 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

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. (See FCA fact sheet [Caregiving with Your Siblings](#).)

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. (See the FCA fact sheets [Guardianships and Conservatorships](#) and [Legal Planning for Incapacity](#).)

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. (See the FCA fact sheet [Finding an Attorney to Help with Estate Planning](#).)

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 (See the FCA fact sheet [Holding a Family Meeting](#).)

Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

E-mail: info@caregiver.org

FCA CareNav: <https://fca.cacrc.org/login>

Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's, and other debilitating disorders that strike adults.

Additional Resources

National Academy of Elder Law Attorneys

www.naela.org

Information on how to choose an elder law attorney and referrals to elder law attorneys.

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