

Family Caring for Family

Navigating the landscape of
caring for your elderly loved one;
and thriving along the way

Agingcare.com[®]

Introduction

It may be that your mother has fallen four times in as many days, or you notice that your father is allowing unpaid bills to pile up on his desk. Perhaps your spouse has been telling the same story over breakfast for the past week-and-a-half—whatever the indicator, you can always tell when there's something not quite right with a loved one.

Whether you are providing hands-on care or overseeing from afar, this guide will help you prepare for and navigate your role as caregiver of an elderly loved one. You will also discover how to approach caregiving for what it is: a journey, during which you and your family will experience the full spectrum of emotions: love, pain, joy, sorrow and, most importantly, hope.

AgingCare.com sprouted from the desire to help people successfully navigate the landscape of being a family caregiver. We aim to nurture these compassionate men and women by connecting them with each other, as well as an ever-growing collection of online resources, both instructive and inspirational.

The creators of this guide: writer, Anne-Marie Botek; designer, Maria Breston; and AgingCare.com experts Cindy Laverty and Carol Bradley Bursack, have gathered and presented the best of AgingCare.com, with the hope that it will enable people taking care of elderly loved ones to flourish and thrive on their path.

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On A Wing And A Prayer: Insights From Caregivers

“You are a Caregiver if you worry about the person you love...Caregivers are those who are the most selfless people in the world...Yes, you are a Caregiver, no matter what people say. You are amazing, and God Bless you for what you are doing.”

“You are a caregiver because you care about him and ultimately, you are the one who is in a position to advocate for him and have his best interests at heart.”

“There is no cookie-cutter formula for the endless roller-coaster ride that is caregiving. We do the best we can with what we have and hope for the best.”

“He’s lucky to have you to love and care and to be his advocate.”

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 1

Am I A Caregiver

Recognizing one’s role as a family caregiver seems like an obvious initial step in the caregiving journey. However, a surprising number of people skip this integral first phase, diving right in to their elder care responsibilities.

In this chapter, you will learn to recognize when an aging loved one needs additional help, how to distinguish between the changes caused by “normal aging” and changes that could signify that something is wrong with an elder, and uncover valuable insights about the four main categories of family caregiver.

Articles in this chapter include:

- When an Elderly Loved One Needs Extra Help
- The Many Faces of Caregiving



When an Elderly Loved One Needs Extra Help

Family members of aging adults typically travel one of two paths to becoming a caregiver: the sudden sprint, or the gradual march. The sudden sprint towards providing care for a loved one is often set off by an unexpected event—a stroke, a fall, complications from surgery—which acts as a catalyst, escalating your family member’s care needs practically overnight.

The gradual march in the direction of caregiving is less abrupt. You can’t say exactly when it began, but you’ve started noticing little changes in how your family member interacts with the world around them. Perhaps they’re getting lost while driving to the grocery store, or they are having trouble keeping track of their medications, or balancing their checkbook—tasks they’ve performed countless times over the years, without any problems.

Whether the change is sudden or gradual, there are certain signs you can look for that indicate when your loved one is having trouble attending to their own needs.

If your family member is consistently exhibiting the kinds of actions and behaviors outlined to the right, they may soon be in need of extra care.

Identifying the presence of these indicators early on will enable you, your aging loved one, and the rest of your family, to come up with a plan to make sure everyone’s needs get met.



22 Common Signs Your Loved One May Need Extra Help

Physical

- Fluctuating weight
- Balance problems
- Poor hygiene
- Sleeping too much or too little
- Unexplained burns or bruises

Home environment

- Unkempt yard
- Unusual carpet stains
- Excessive clutter (newspapers, piles of junk mail)
- Unusual odors (urine, garbage)
- Not enough food in the house
- Failure to turn off stove or water after use

Emotional

- Mood swings
- Abusive behavior; outbursts
- Lack of motivation
- Uncharacteristically anti-social behavior

Cognitive

- Confusion
- Memory loss
- Repetition
- Hallucinations

Other

- Dents/scratches on the car
- Unfilled or untaken prescriptions
- Unpaid bills

Normal Aging, or Alzheimer's Disease: What's the Difference?

As a loved one ages, one of the questions that may come up for you and your family is how to tell the difference between the cognitive changes associated with “normal aging” and those that could signal serious underlying health conditions, such as dementia.

At this time, there's no definitive way to distinguish between benign memory slips, Alzheimer's or other forms of dementia. Consider this as a general rule of thumb: occasionally misplacing the car keys is normal, while forgetting what to do with them is not.

Here are a few additional indicators that your loved one's cognitive troubles may be caused by something more serious than the simple advancing of age:

Signs That Cognitive Troubles May Be More Than 'Old Age'

- 1 Bad judgment
(poor financial decisions, public outbursts)
- 2 Movement issues
(stiff movements, hunched posture)
- 3 Loss of inhibition
(saying or doing socially inappropriate things)
- 4 Language problems
(can't form coherent sentences)
- 5 Hallucinations and delusions
(seeing things that aren't really there)
- 6 Trouble performing familiar tasks
(can't remember how to get to the doctor's office)
- 7 Memory loss that interrupts daily life
(regularly forgets recent conversations)

Ultimately, it's up to you and your family to determine if, and when, a loved one's cognitive issues warrant investigation by a medical professional.



The Many Faces of Caregiving

There is no one specific definition of a caregiver; every individual situation is unique. Some caregivers start off by assisting a loved one with their finances, cleaning their house, or helping them get to and from their doctor's appointments. Or, a caregiver might immediately take over assisting an elder with bathing, getting dressed and going to the bathroom.

A caregiver could live in the same house, or reside 3,000 miles away. They may be taking care of two aging parents, one ill spouse, or three children and a parent at the same time.

The possible permutations are endless, but there are four main caregiver categories that are widely recognized. Each grouping has its own set of challenges and considerations.

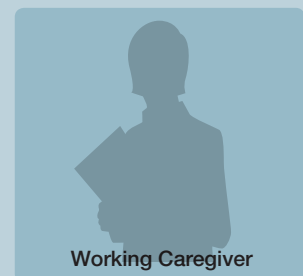
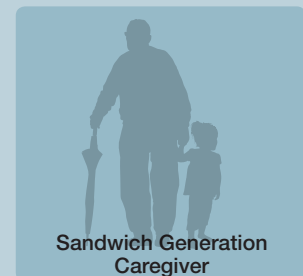
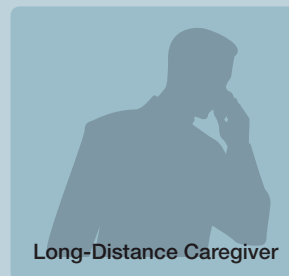
“A caregiver is a person who takes on at least some part of the responsibility for the welfare of someone sick, elderly or disabled. If the title fits, wear it proudly my friends.”

— Carol Bradley Bursack, AgingCare.com expert, author and caregiver

Which Kind of Caregiver Are You?

No matter which of these group(s) you fall in to, you are a caregiver. As a caregiver, you will be a source of invaluable physical, emotional and spiritual support for your elderly loved one.

The journey may be short, or it may be long. There will be ups, downs and all-arounds. Ultimately, [caregiving is a legacy to be proud of.](#)





The Long-Distance Caregiver

These individuals look out for elderly loved ones who live in a different city, state, or country. But, just because they live far away doesn't mean these caregivers aren't often responsible for their family member's finances, medical care and personal needs. One of the most difficult aspects of being a long-distance caregiver is how to keep an eye on a loved one from afar. When you only see an elderly parent a few times a year, how can you make sure they're getting the care they need? In these types of situations, [geriatric care managers](#) and [patient advocates](#) can be invaluable resources for family caregivers.



The Sandwich Generation Caregiver

The aging of the baby boomer cohort has transformed the term, "sandwich generation," into somewhat of a buzzword. These men and women are so-named because they are, quite literally, sandwiched between taking care of their own young children, and looking after one or more elderly parents. They may work, they may not. The challenge for these individuals: [balancing the care needs of elderly parents and young children](#).



The Spousal Caregiver

The vow, "in sickness, and in health," takes on a whole new meaning when a person finds themselves taking care of a spouse with a serious illness. When a life partner becomes a life patient, a caregiver must deal with a host of heart-wrenching problems, from [intimacy issues](#) to how to handle unexpectedly altered roles.



The Working Caregiver

["Should I quit my job to take care of my parents?"](#) is the quintessential dilemma of the working caregiver. In an era when adults of both genders have a presence in the workforce, the number of working caregivers is on the rise. Holding down a nine-to-five while making sure an elderly loved one is looked after is a seemingly impossible task; one that can be made more or less difficult, depending on the culture of the company that a caregiver works for. Here are some common [issues that people face when caregiving and work obligations collide](#).

"A caregiver is that rare and special individual who says "yes" to helping, supporting and caring for a loved one. A caregiver offers the most special gift of all to another human being who is in need of care."

— Cindy Laverty,
AgingCare.com expert

Additional Reading

AgingCare.com Articles:

- When Do You Become a Caregiver? [Read](#)
- Discussing Caregiving With Your Boss [Read](#)
- Facing Reality: Caregiving Has Changed Your Life [Read](#)
- Thrust into Caregiving: How to Adapt, Survive and Thrive [Read](#)

Questions and Discussions From Other Caregivers:

- Am I a caregiver? [Read](#)
- My parents want me to quit my job to care for them, but I can't afford to. What should I do? [Read](#)
- Any advice for a new and frankly terrified caregiver? [Read](#)
- Is caring for elderly parents harder than caring for children? [Read](#)

On A Wing And A Prayer: Insights From Caregivers

“Dad is 65 and was so stable for years. All of this, needing care, legal matters...everything seems so sudden and I was completely unprepared.”

“My dad did the same thing yours did: he bought a mobile home, paid too much and ended up losing a lot of money. To help him, you will need a POA for both medical and financial.”

“If the POA/Durable POA kicks in when the person becomes incompetent, then you should contact the originating attorney and discuss next steps. He can help you decipher what your power is.”

“We waited too long to get a POA, Health Directive or Living Will. Now she is 87 with Alzheimer’s and we cannot make decisions on her behalf.”

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 2

Getting Organized Before Needs Escalate

In caregiving, a certain amount of unpredictability should be expected. Effective caregivers know how to plan ahead so that they can quickly adapt to unexpected changes in their aging loved one’s health and care needs.

In this chapter, you’ll discover which legal documents need to be in place to ensure that your loved one’s financial and health care wishes are honored. You will also learn how to prepare for your new role as a caregiver; legally, financially and emotionally.

Articles in this chapter include:

- Helping an Aging Family Member Plan for the Future
- What YOU Need to Do Before Assuming the Role of Caregiver



Helping an Aging Family Member Plan for the Future

The importance of advance planning for aging adults (especially those suffering from chronic illnesses) cannot be overstated. Without the right legal and financial documentation, caregivers and their loved ones could be faced with a host of problems in an emergency.

Doctors may refuse to discuss important medical information with a caregiver, a dying elder may not get the end-of-life care they desire, and control over an incapacitated loved one's bank accounts and property could be given to a complete stranger.

You can help your loved one plan for their current and future medical and financial needs by working with them to prepare six essential legal documents, which are described in further detail on the next page.

6 Must-Have Legal Documents for Family Caregivers

Medical Documents

- HIPAA Authorization
- Healthcare POA
- Advance Healthcare Directive

Financial Documents

- Financial POA
- Trust
- Will

An elder law attorney can assist with the preparation of these documents, as well as provide valuable guidance to help you plan for the future, given your loved one's individual situation and preferences.

Having the necessary documents in order before a medical or financial disaster strikes can make an extremely difficult situation just a little bit easier to navigate. Knowing that you're carrying out your loved one's wishes, even though they may not be able to voice them, can ease the crushing feelings of guilt and doubt that many caregivers experience in these situations.

“The goal is to become empowered in your role and this begins with you. The caregiving journey is about you. It's not about all of the things you have to do and the challenges that present themselves. It's about the value you place on yourself.”

— Cindy Laverty, AgingCare.com expert

Important documents for managing **medical care**

- **HIPAA Authorization:** The Health Information Portability and Accountability Act (HIPAA) aims to protect medical record privacy. This law prevents doctors and other medical professionals from discussing an individual's health information with anyone but that person. Even caregivers can't access a loved one's medical records, or talk to their doctor, until they sign a HIPAA form. Fortunately, this document is easy to obtain; most doctor's offices have copies on hand.
- **Healthcare Power of Attorney (POA):** This important legal document allows a person to grant legal authority to a trusted relative (i.e. the family caregiver), or friend, to make health care decisions on their behalf. A person with healthcare POA can determine (among other things) where an elder lives, what they eat, who bathes them, and what medical care they receive. (*see note below)
- **Advance Healthcare Directive:** An advance healthcare directive combines a healthcare POA with a living will. A living will outlines how an elder wishes their end-of-life care to be managed (i.e. aggressive medical care versus hospice care), and may also include a Do Not Resuscitate (DNR) order, or instruction not to insert a feeding tube if they become incapable of eating on their own. Learn how to [Avoid the Number One Mistake Elders Make With Healthcare Directives](#).

Important documents for managing **finances**

- **Financial Power of Attorney (POA):** A financial POA gives a trusted relative (i.e. the family caregiver), or friend, the ability to make legally-binding decisions about a person's financial assets. An individual with financial POA has the authority to manage an elder's finances, which may include paying bills, liquidating assets to cover expenses, or making other investment decisions. (*see note below)
- **Trust:** Trusts—essential estate planning documents that specify how a person wants certain assets to be disbursed—come in several different varieties. Each type of trust has its own rules and requirements that affect how funds are distributed after a person passes away. The main difference between a will and a trust is that a trust can be enacted while the individual is still alive, or after they have died. A will only goes into effect after a person has passed on.
- **Will:** There are many different kinds of wills, each with different stipulations regarding how assets and property are to be doled out after a person dies. As previously mentioned, a will can only be activated by the death of the individual. For more information on writing wills, see [What is a Will and Why Every Senior Should Have One](#).

**An additional note about POA: There can be confusion with regards to the difference between “durable” and “nondurable” powers of attorney. A durable POA is one that endures a person's incapacitation. This means that, until a person either passes away or is able to regain control of their own affairs, the POA remains in effect. This is as opposed to a nondurable POA, which becomes null upon a pre-defined contingency—such as a particular date, or in the event of a person's incapacitation.*

For additional information on POA, see: [Things You Can and Can't Do With POA](#)

What YOU Need to Do Before Assuming the Role of Caregiver

Being a family caregiver is not for the faint of heart.

For those that take on this invaluable role, there will be moments of both heartbreak and healing. As one AgingCare.com caregiver describes it: “This life is difficult. We learn. We grow. Hopefully the process is coupled with compassion, not only for those we care for, but also for ourselves.”

The best way to cope with caregiving’s emotional rollercoaster, and thus avoid burnout, is to plan ahead.

5 Questions to Help Prospective Caregivers Plan Ahead

Before blindly rushing in to caregiving, be sure to identify your own physical, emotional and spiritual needs. Develop a strategy for making sure these needs get met while you’re taking care of your elderly loved one.

1. Do I have children at home? What are their needs?
2. Do I have a supportive spouse or partner, a negative partner or no partner? How might this relationship affect my caregiving and how could my caregiving affect my relationship?
3. Am I a social person, a loner or somewhere in between? How will I fit in my “alone time,” my social life, my work obligations and my family’s needs with my caregiving?
4. Where do I need to be able to draw the line and say, “I can do this much and no more?”
5. Will I continue to be vigilant about maintaining my own health, or will I let it slip?



Of course, time is a luxury that many caregivers can’t afford—especially those who are thrown into their role when an unexpected event incapacitates an elderly family member. If you find yourself in this particular situation, attend to your loved one’s immediate needs first. Once things have calmed down, take a quiet moment to pinpoint and plan for your needs.

It’s vitally important that you answer the above questions honestly. Guilt and an overwhelming sense of obligation may compel you to be dishonest with yourself (After all, your parents took care of you, shouldn’t you take care of them?). But, biting off more than you can realistically chew is bad for the overall wellbeing of both you and your loved one.

Why it's ok to say “no” to caregiving

It is possible to say ‘no’ to taking care of an elderly loved one without coming off as uncaring or selfish.

Depending on your situation, passing the caregiver baton (whether temporarily, or permanently) to another family member or a professional caregiver can be the most mature and loving decision you make regarding your loved one's care.

Caregiver coach, Cindy Laverty, puts it this way, “You might think, ‘I can't say no to mom.’ But your mom probably said no when she was taking care of you as a child. Sometimes in life, the answer has to be no.”

Ultimately, it's up to you to candidly evaluate your ability and willingness to commit to the role of caregiver. Doing so can save you from burning out and, if handled with love and honesty, may even deepen your relationship with your loved one and the rest of your family.

If you're a new caregiver, and you feel as though the role is already giving you too much to handle, [learn how to regain control of your life](#).

The first thing you need to do if you've said “yes” to caregiving

If you do decide to accept the responsibilities of primary caregiver, you can't—and shouldn't—try to tackle everything on your own. Identifying all available respite and support resources as soon as you possibly can is a must. Here are just a few of the places and people that family caregivers can turn to for help:

- Family
- Friends
- Neighbors
- Local support groups
- Online forums like AgingCare.com/Caregiver-Forum
- Local Administrations on Aging
- National Council on Aging
- The Alzheimer's Association



Planning for your financial future

Caring for a family member can deal a serious blow to a caregiver's personal finances.

Sixty-two percent of family caregivers say that the cost of caring for an elderly loved one has impacted their ability to plan for their own financial future, according to a recent AgingCare.com survey.

Even with government funded programs (such as Medicare, Medicaid and Social Security) to help foot the bill, out-of-pocket costs for a senior's medical care can skyrocket to tens-of-thousands of dollars in their last five years of life.

That's why it's essential that you take steps to secure your personal finances as soon as you possibly can.

Here are a few pointers for managing your money while caregiving:

- If you are a working caregiver, maximize your employer benefit programs
- Keep your own future long-term care needs in mind—you may want to consider purchasing [long-term care insurance](#)
- Make sure you have the right life, property and casualty insurance
- Designate your own financial and healthcare POA
- Set up your personal will and trust

62%

of family caregivers say the cost of caring for an elderly loved one has impacted their own financial future.

— AgingCare.com Survey

For more information on planning for your own financial future, see [Financial Planning Tips for Caregivers](#).



Additional Reading

AgingCare.com Articles:

- Why Elder Law Attorneys Aren't Just for Seniors [Read](#)
- 7 Legal Issues that Caregivers Face [Read](#)
- Family Feuds Over Power of Attorney [Read](#)
- 19 Free Services for Seniors and Caregivers [Read](#)

Questions and Discussions From Other Caregivers:

- Can you revoke a Power of Attorney? [Read](#)
- What to do when a parent refuses to make a will? [Read](#)
- Should I be handling Dad's finances? If so, how? [Read](#)
- How do you invoke POA when a parent is no longer making sound financial decisions? [Read](#)

On A Wing And A Prayer: Insights From Caregivers

"If your mother resists, call in a trusted friend, clergy member, or doctor who can act as a "buffer" as you explain to her why she needs to make this change. Give her limited options that will work for you. (ie: "mother, we either need to do this or that...choose one.")

"There are no easy answers in this situation. I would speak the truth in love that their situation is not safe."

"She is fighting you because her world is confusing and all she's got left is a feeling of independence."

"Have the doctor declare him incapacitated and list the reasons why; use that during your family meeting. By focusing on factual reasons, it's a lot easier to communicate because the discussion becomes about the list and not anyone's opinion."

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 3

Communicating With Family About Important Issues

Solid communication skills are a vital asset for every family caregiver. Being able to politely and effectively discuss difficult issues with an elderly loved one and the rest of the family can keep relationships with relatives strong, in spite of the challenges that arise when caring for an aging adult.

In this chapter, you will learn why aging adults refuse help from younger family members, as well as how to overcome communication barriers with an elderly loved one. You'll also uncover strategies for keeping the peace while conversing about controversial elder care issues with the family.

Articles in this chapter include:

- Convincing an Elderly Loved One to Accept Help
- Keeping the Peace While Discussing Difficult Topics with Family
- Death, Driving and Dollars: How to Discuss Taboo Topics with Elderly Loved Ones
- How to Handle Criticism from Family Members

Convincing an Elderly Loved One to Accept Help

For many aging adults, the progressing years represent a series of increasingly hard-to-handle losses: loss of energy, loss of mobility, loss of hearing, loss of financial independence. These losses gradually chip away at their sense of freedom and can deal a significant blow to their self-esteem.

Combine that with the fact that well-meaning younger family members tend to offer help in a way that reminds their loved ones of their advancing age, and you've got a recipe for interpersonal conflict.

This is the main reason why older people refuse help, and act out when their younger family members offer to lend a hand, according to Oregon State University professor, Michelle Barnhart.

“When we offer assistance to an aging person, sometimes we do so in a way that challenges their identity as an independent adult,” says Barnhart. “Treating someone as a stereotypical ‘old person’ makes them say, ‘I don’t feel old, why are people treating me like this?’ This can cause serious communication issues.”

Barnhart and her colleagues conducted in-depth interviews with elders, adult children and caregivers in order to examine why aging adults so often reject outside assistance.

They discovered that, when an older adult’s identity is threatened, he or she may lash out—engaging in potentially dangerous behaviors to prove their youth.

4 Ways Elders Retaliate When Younger Family Members Try To Help:

- **Hashing it out:** Outright arguments are a common way for seniors to express their frustration at being categorized as old. An elder will try to persuade others that they are not as old or incapable as they seem.
- **Proving themselves:** Mark, one of the interviewees participating in the study, repeatedly offered to help Bea, his 82-year-old mother-in-law, with household maintenance that required a ladder because he was afraid that she would lose her balance and fall. Bea responded by rebuffing Mark’s request, proudly telling him every time she used the ladder to do something.
- **Preventing participation:** When 89-year-old Abbie’s (another interviewee) cardiologist started addressing her two adult daughters instead of her during an appointment, she banned them from the exam room. “I wanted to grab him by the collar and say, ‘Look, talk to me! I’m the patient!’” she says. “But that was easily corrected. They don’t go in with me anymore.”
- **Hiding their indiscretions:** After Abbie’s daughters tried to get her to stop driving, she would pretend to follow their advice, while secretly driving her sister around.

As a caregiver, your challenge will be to make sure your loved one is safe, healthy and getting the help they need. You need to be able to do this without overstepping your boundaries, which could cause them to become resentful and resistant to your assistance.

“When we offer assistance to an aging person, sometimes we do so in a way that challenges their identity as an independent adult.”

— Michelle Barnhart, Oregon State University Professor

Here are some tips for taking charge, without taking over:

- **Ask what they need help with:** If a loved one believes that asking for help was their idea, they may be more likely to accept assistance. If you start off by lending a hand with just those things that your loved one admits to needing help with, they may be more receptive to any future suggestions you have regarding their need for outside assistance.
- **Show respect:** Respect is the foundation upon which all good relationships are built. Ask your loved one’s permission before rushing in to “save the day.” Even if you want to sit in on a loved one’s doctor’s appointment, inquire about their feelings first. If they don’t want you in the exam room, wait outside and talk to their doctor about your concerns once the appointment is over.
- **Let them contribute:** Even if a loved one does allow you to assist them with a particular task (say, folding the laundry), let them pitch in. It may make the process less efficient, but being able to contribute can renew an elder’s sense of purpose and worth.

But remember, safety should always be your ultimate aim. If you have to assume total control of a task to make sure your loved one

Mom usually resists my help, but the other day, I looked her in the eye and said, “Do you trust me to take care of you?” She looked back at me and said, “Yes!”

— AgingCare.com member



Death, Driving and Dollars: How to Discuss Taboo Topics with an Elderly Loved One

No one relishes the thought of pondering death for too long. Aging adults don't want to consider what giving up the keys to the car will mean for their independence. And, thanks to the prevalence of identity theft, financial information always has an aura of silence surrounding it.

However, as you begin taking on more and more responsibility as a caregiver, there will come a time when you will have to discuss these types of issues with an aging family member.

Here are **8 strategies for discussing sensitive subjects** with an elderly loved one:

- 1. Don't give advice unless it's asked for:** This is an especially important tip for adult children who are looking after aging parents. Your mother and father are used to providing you with advice and guidance. When this dynamic begins to shift, it may start to lower their self-esteem and make them feel out-of-control. Getting an outside expert — such as a financial advisor, or elder law attorney — to provide professional guidance can make an elder more receptive to new information.
- 2. Pick your battles:** It's likely that your loved one needs help with multiple tasks — don't try to tackle all of them in a single conversation. Prioritize your loved one's needs and address them over a series of discussions. This will ensure that each talk is focused on identifying a single problem and all of its potential solutions.
- 3. Listen to what they're saying:** Make sure you're really listening to what your loved one is saying. Try not to interrupt, or fill the silence during a conversation. When it's your turn to speak, summarize what you think your loved one just said and then ask them if you have correctly interpreted their sentiments.
- 4. Accept differing viewpoints:** Expect and accept disagreement, especially when discussing hot-button topics. Acknowledge your loved one's questions, concerns and viewpoints. Try to come up with a compromise that everyone can accept.

When Dementia is Involved...

One Caregiver's Story

Dad was adamant. He was waiting for his medical degree to come from the University of Minnesota and wondered why it was taking so long. I did what I usually did, and waited a few days to see if this episode of deluded thinking would pass. It did not. So, I went to my computer and designed a medical degree with my dad's name on it, scribbled some "signatures" on the bottom, put it in a mailing envelope and brought it to him, in the nursing home, the following day. He was delighted.

One day, a couple of years into this saga, a psychiatrist caught wind of what I was doing. He chewed me out royally. I was supposed to ground Dad. Bring him back to reality. Redirect him. I had no business playing Dad's game.

Hogwash, I thought. I know my dad. I know he is not capable of coming into my "reality" and I wasn't going to torture him by trying to drag him along. If I argued that he was delusional, he would feel degraded and disrespected. It made no sense to me. I still had my brain. Why couldn't I put his anxiety to rest by traveling into his world — his "reality"?

The funny thing is, a few years later, a different psychiatrist stood looking at Dad's award and degree

(continued)

5. **Speak calmly and clearly:** Especially if things begin to get heated, avoid raising your voice or shouting during a conversation. An argument can quickly escalate if either party starts acting flustered. Also, when speaking to older adults with hearing issues, it's important to keep your voice low and to make sure to properly announce. This will smooth the communication process by ensuring that your loved one is literally hearing what you're saying.
6. **Don't patronize:** No one likes to be talked down to, especially if they've been living decades longer than the person they're conversing with. Even if you're talking to someone who suffers from Alzheimer's, or some other form of dementia, don't infantilize them by speaking to them the same way you would speak to a child.
7. **Choose your setting carefully:** Plan out where you want the conversation to be held. Pick an area that is quiet and has few distractions (television, radio, too many people). Make sure you're facing your loved one at all times.
8. **Put yourself in their shoes:** Remember, your loved one is probably feeling as though they are losing control over their own life. In their mind, their freedom and independence are being threatened. Be mindful of these feelings and approach the discussion with sensitivity and empathy.



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covered wall. A nurse stood next to him.

"I didn't know he was a doctor," the doctor said.

"He's not," the nurse said, with a grin. The doctor burst out laughing. Later he asked me where I learned my "technique."

"I'm his daughter," I said. That's all I needed.

Now there is an actual theory about this called "validation theory." It makes me smile. I didn't need a theory to know what Dad needed. I just needed love.

Yes there were times when I would try to explain true reality, but I chose my battles wisely. I tried to keep him from seeing television news because he would insist that the war going on (there's always a war going on somewhere) was in our town, right outside his window. I would calmly say, "I'm sorry you can't believe me, but we are okay. We'll talk about it another time."

My point is this: Dad's reality was as real to him as mine is to me. Why should I make his life miserable by continually telling him he is wrong, when going with the flow was not hurting anyone else, and it was making Dad's life a little more bearable? I'm his daughter. He would have done as much for me.

— Carol Bradley Bursack,
AgingCare.com expert

Keeping the Peace While Discussing Difficult Topics with Family

When a loved one starts to show signs of needing additional care, there are many issues for family members to discuss, and a host of important decisions that need to be made. The gravity and potential implications of these decisions can make for some contentious conversations—even among the most congenial clans.

Here are a few techniques for keeping the peace when discussing an elderly loved one's care needs with the rest of the family:

- Accept that not everyone wants to be involved:** For various reasons, not everyone in the family may want to be involved in planning and executing an elderly loved one's care strategy. Whatever their reasons for wanting to be excluded, it's important to respect their decision. You don't have to agree with it, but allowing resentment to build over unhelpful family members will only serve as an energy drain for those who do wish to provide assistance. A little extra understanding can go a long way in building your acceptance; the article [Top 3 Excuses From Family Who Won't Help With Caregiving](#) may help.
- Pick a location:** Family meetings should be conducted in a space where every member feels welcome and comfortable. If the family doesn't have the time or resources to physically gather together in one space, remote conferencing tools, such as Skype and FaceTime, can be used to ensure that everyone who wishes to participate in the discussion is able to do so.
- Plan ahead:** Pick a set of talking points to cover during the conversation and make sure each point is addressed.
- Consider outside help:** If you know that your family has a tendency to be combative, you may want to think about asking an objective third-party, such as a family friend, a social worker or a clergyman, to sit in on the meeting and help facilitate the conversation.
- Give everyone a say:** All family members should be allowed to voice their opinions and emotions without fear of criticism or ridicule.

8 Important Talking Points to Include in a Family Meeting

- 1 An up-to-date medical report on your loved one.
- 2 The elder's wants and needs with regards to care and support from the family.
- 3 Where a loved one will live (i.e. in their home, with another family member, in assisted living).
- 4 How much an elder's care will cost, and how that cost will be covered.
- 5 What the primary caregiver needs in terms of assistance and support from the family.
- 6 How much time each family member has to visit, or care for, an elderly loved one.
- 7 What other resources are available to help the primary caregiver.
- 8 Take time to allow each family member to share their emotions about the situation.

- Identify and outline roles and responsibilities:** An individual family member's role will likely be defined by their relationship with an elderly loved one, how much time they have to devote to helping out, and where their talents lie. For instance, if you have an uncle who is an accountant, but lives in a different state, he may be the ideal candidate to manage your loved one's finances.
- Summarize the important decisions:** As you would after a work meeting, recap what was talked about and what decisions were made, both verbally and in writing. It may also help to create a calendar that identifies each person's responsibilities and commitments. This will ensure that all family members leave the gathering on the same page with regards to how they fit in to an elderly loved one's care plan.
- Don't strive for perfect harmony:** Family meetings won't solve every problem faced by family caregivers. Go into a gathering with the knowledge that not all questions are answerable and not all plans will work. Accept the fact that family members will disagree and arguments are likely to break out. This will allow you to keep a cool head and steer the conversation back to the problem at hand, should things start to get off-track.
- Discuss how to keep family members in the loop:** Come up with a strategy for keeping family members informed of any unexpected changes in an elderly loved one's status or care. This can include actions, such as sending out a periodic [Care Report](#) to update everyone on a loved one's condition, or setting up a phone tree to spread the word in the event of an emergency. Also, since family meetings are most effective if they are held on a regular basis, make a tentative schedule for when the family should gather again to re-evaluate a loved one's care.

Despite your best efforts to keep the peace, the challenges involved in planning, paying for and carrying out a loved one's care may still cause some division.

For example, it's not uncommon for siblings to disagree on how an elderly parent should be cared for, or for family members who live far away to be in denial about an aging loved one's declining health.

Update Family and Friends with a Care Report

It's a quick and easy way to keep family and friends updated on your loved one's care and well-being.

[Send a Care Report](#)

The screenshot shows the 'Care Report' form on the AgingCare.com website. The form is titled 'Send a Care Report, it's quick & easy...' and includes a dropdown menu for 'This Care Report is about:'. Below this are five horizontal indicators for 'Mood', 'Finances', 'Mobility', 'Memory', and 'Eating', each with a slider from 'Bad' to 'Good' and a 'Note (Optional)' field. At the bottom, there are fields for 'Name' and 'Email Address' to send the report to, and a 'SUBMIT' button. The footer contains copyright information for AgingCare, LLC.

How to Handle Criticism from Family Members

It's an unfortunate reality of caregiving that the caregiver will always be a potential target for criticism, especially from family members and friends who don't understand what it's like to provide care for an elderly loved one.

If you find yourself in this situation, there are a few strategies you can use to cope with any sharp remarks:

- **Don't make it personal:** Try to avoid internalizing any insults you receive, whether they come from an elderly loved one that you're taking care of, another family member, or a friend. In all likelihood, the source of their venom has nothing to do with you.
- **Accept that you can't make everyone happy:** It's cliché, but especially true for family caregivers: if you try to please everyone, you will end up pleasing no one. Family members and friends will not always agree with your decisions regarding a loved one's care. While it's a good idea to take into account the viewpoints of others, it's also important to learn how to [trust your gut](#) and stand by your choices.
- **Understand that criticism is inevitable:** No one relishes receiving negative feedback, but unfortunately it's an inevitable consequence of assuming the caregiver role.
- **Turn your frown upside down:** You've probably heard it before, but research has consistently shown that even a fake smile may provide mood-boosting benefits and can help you mentally and physically relax.
- **Don't be a pushover:** Criticism may be unavoidable, but that doesn't mean that you should tolerate abusive behavior. If a family member is consistently hurling hurtful remarks in your direction, calmly tell them that you refuse to be treated that way and physically remove yourself from their presence.
- **Seek support:** Receiving a harsh critique—especially when it comes from a family member or close friend—can be difficult to cope with. Many of those who find fault with your caregiving decisions probably don't fully understand the spectrum of emotions and stress that weigh on a caregiver's heart and mind. It's not their fault; they've just never been in your shoes. One of the best ways to cope with criticism is to find an outlet where you can share your experiences and receive honest feedback from men and women who've been family caregivers before. Online support groups, such as the one on [AgingCare.com](#), can allow you to tap into an ever-present wellspring of encouragement, inspiration and guidance from fellow caregivers.

It may be hard, especially in the beginning, but eventually you will develop your own process for coping with criticism in a healthy, productive way.

“I appreciate your integrity in keeping [AgingCare.com](#) a pure site for its members, and one that really helps us to connect with each other and offer mutual support during such difficult times. Sometimes, by offering others advice and support, it actually makes us stronger in dealing with our own situation. I know it has for me.”

— AgingCare.com member

Additional Reading

AgingCare.com Articles:

- Switching Roles: Coping with Your Rebellious Aging Parent [Read](#)
- When Siblings Can't Agree on a Parent's Care Needs [Read](#)
- How to Get the Rest of the Family to Help With Caregiving [Read](#)

Questions and Discussions From Other Caregivers:

- My parents live in filth but refuse help, what can I do? [Read](#)
- How do you deal with difficult relatives? [Read](#)
- How do you deal with your feelings of resentment when your siblings won't help? [Read](#)
- How do you deal with an aging parent's constant negativity? [Read](#)

On A Wing And A Prayer: Insights From Caregivers

“There is nothing wrong with switching doctors if you are not getting the service that you or your insurance is paying for. Start asking for referrals from friends and co-workers. Ask if they know a gerontologist – and write them down, especially if two people recommend the same doc.”

“A Medicare supplement plan fills the gaps from what Medicare does not pay. Medicare pays 80% and a supplement will usually pay the other 20%. If you can't afford the premiums, check with your local Office on Aging for recommendations.”

We need to go to doctors who are professional, listen, and respect both the patient and his or her family.”

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 4

Navigating the Healthcare System

As a caregiver, one of the most important (and challenging) responsibilities is that of organizer and advocate for a loved one whenever they encounter the confusing maze that is the healthcare system.

In this chapter, you will learn more about the different ways to pay for healthcare (including government financial aid), how to choose the right medical professionals to take care of your loved one and discover tips for managing medications and coordinating care.

Articles in this chapter include:

- Government Programs to Help Pay for Elder Healthcare
- Should You Stay or Go: Knowing When to Accompany a Loved One to the Doctor
- Assembling and Managing a Loved One's Healthcare Team
- Guide to Managing Multiple Medications

Government Programs to Help Pay for Elder Healthcare

It's no secret that the cost of healthcare in the United States is staggering, especially among the aging population.

The average elder will pay nearly \$39,000 in out-of-pocket medical costs during their final five years of life, according to a 2012 study conducted by researchers at the Mount Sinai School of Medicine.

And that's just the average aging adult.

According to study authors, the typical elder in the top 25 percent of medical expenditures shelled out about \$101,791 in the five years preceding their death.

Thankfully, aging adults and their families don't have to rely solely on personal assets (life insurance policies, long-term care insurance and retirement accounts) to pay for healthcare. There are also a variety of government-funded financial resources available to help elders cover the cost of medical intervention.

Most families use some combination of personal assets and government financial aid to pay for a loved one's healthcare expenses.

Government Programs Discussed in This Chapter

Medicare

Our country's health insurance program for people age 65+

Medicaid

Government assistance for low-income Americans

Social Security

Benefit to individuals who are over age 62 and were actively employed in the workforce for at least 10 years

Veteran's Benefits

Available to those over age 65 who were honorably discharged from military service



Overview of Government Assistance Programs Available to Elders

Medicare: Medicare is our country's health insurance program for people age 65, and over. Similar to traditional health insurance, the government-funded Medicare program does not cover 100 percent of an aging adult's health care costs. Multiple coverage and deductible options are available, with varying levels of required monthly premiums. (People who are younger than 65 may also be able to qualify for Medicare, if they have certain disabilities, or suffer from end-stage renal disease)

There are technically four [different parts to Medicare](#):

- **Part A** covers inpatient hospital stays, hospice care, home healthcare and care in a skilled nursing facility.
- **Part B** deals with outpatient hospital care, lab tests, x-rays, home-based physical therapy, doctors' bills, ambulance services, durable medical equipment, chiropractic care and certain prescription medications.
- **Part C** closes some of the gaps in Medicare coverage—the portion of healthcare costs not covered by Medicare—and may be able to reduce an elder's out-of-pocket expenses. Part C plans are also referred to as “Medigap” or “Medicare Advantage.” Some elders choose to apply for Medicare Advantage plans that allow them to receive all of their benefits via a private insurance company. These plans are vetted and approved by Medicare, even though they are purchased through private insurers. Choosing a Medicare Advantage plan can be confusing. It's important to make sure that whatever plan your loved one selects will cover their unique medical needs.
- **Part D** delivers prescription drug coverage to elders who qualify for Medicare.

An elder must apply for Medicare in order to receive coverage. The initial enrollment period begins three months before a person turns age 65, and continues for three months after. If enrollment is not completed during this timeframe, Medicare medical insurance – as well as prescription drug coverage – could be delayed, and an applicant may be charged higher premiums. Following the initial enrollment phase, annual enrollment periods (usually occurring from October-December) allow an elder to select a new plan, or make changes to their existing plans. However, note that Parts C and D require separate enrollment periods. (Learn more about the ins and outs of [Medicare open enrollment](#).)

Note on the Medicare PACE Program: In some parts of the country, elders can apply for Medicare's Program of All-Inclusive Care for the Elderly (PACE). This program is meant to offer aging adults who would otherwise need to go into a nursing home a package of benefits that would allow them to be taken care of at home. Learn more about how [Medicare's PACE Program Provides Extra Benefits for In-Home Care](#).

Understanding the Medicare Alphabet

Part A

Inpatient hospital, hospice, home health care, skilled nursing facility

Part B

Outpatient, lab tests and x-rays, physician bills, medical equipment

Part C

Also known as ‘Medigap’ or ‘Medicare Advantage’; helps cover out-of-pocket expenses otherwise not covered by Medicare

Part D

Prescription drug coverage

Medicaid: Medicaid is a financial assistance program, which helps low-income Americans pay for healthcare. A person's income and available assets are what determine whether or not they qualify for coverage under Medicaid. Medicaid is a federal government program that is administered by each state individually. Elders should contact their local Department of Social Services for more information on eligibility requirements, and to begin the Medicaid application process.

In the event that the cost of their care becomes too burdensome, an elder may have to go on both Medicare and Medicaid simultaneously; these individuals are referred to as “dual-eligibles.”

Aging adults who must pursue long-term care in a skilled nursing facility often turn to Medicaid to help cover the cost, as Medicare does not offer benefits for extended nursing home stays. In these instances, there is a five-year look back period, during which the government will evaluate all income and assets over the last five years to determine an elder's eligibility to receive Medicaid benefits. Individuals in this situation will have to ‘[spend down to Medicaid](#),’ in an approved way—meaning that an applicant may not give away money or property for the five years leading up to their application, or risk incurring a penalty. Consequently, there is often a great deal of confusion with regards to the best way to go about spending down an elder's assets so that they qualify for assistance.

Social Security: Currently, Social Security benefit payments are available to individuals who are over age 62 and who were active in the workforce for at least 10 years. Monthly payment amounts are allotted based on how much income the recipient made while working, as well as how early they applied to receive benefits (the longer a person waits to apply, the greater their benefits will be). There are no restrictions on what these funds can be used to pay for.

Veterans Benefits: An elder who served in the military, is over age 65, has a limited income, and wasn't dishonorably discharged may be able to receive financial assistance, in the form of a pension, from the Department of Veterans Affairs (VA). In addition to this money, aging veterans who need long-term care may also be eligible for Aid and Attendance or Housebound benefits which can be used to pay for home health care, assisted living expenses and nursing home care. Learn more about how a [Veterans Aid and Attendance benefit can be used to pay for long-term care](#).

Enrolling in government programs can be a confusing process. It's often difficult to determine which plans best fit your loved one's individual medical and financial needs.

The articles at the end of this chapter provide a few additional insights to help guide you through the process of selecting and signing up for government assistance.

A Special Note For Caregivers

Medicaid's ‘cash and counseling’ program allows family caregivers to receive pay for providing care to an elderly loved one. To learn more about this program, and how you might qualify, read the article [Medicaid's ‘Cash and Counseling’ Allows Pay for Family Caregivers](#)

Should You Stay or Go: Knowing When to Accompany a Loved One to the Doctor

Caregivers often agonize over the question of whether or not they should accompany their loved one to the doctor; balancing the desire to become more educated about an elder's care with not wanting to unnecessarily step on anyone's toes.

A recently published study from the Johns Hopkins Bloomberg School of Public Health sheds some light on this issue, illuminating a few of the habits and outcomes of seniors who visit the doctor with a caregiver companion.

Companions common, but not always needed

The study, conducted on Medicare beneficiaries, found that only one-third of elders who were accompanied on doctor's visits actually needed their companion to assist them with activities, such as moving around, or going to the bathroom.

Overall, 9.5 million elders were found to be regularly visiting the doctor with a medical wingman (or woman) from their family, and for good reason.

There are a host of benefits to having an extra set of eyes and ears at the doctor's office, particularly if a loved one is struggling with conditions, such as hearing loss, or dementia, which may inhibit their ability to understand what the physician is saying.

Shifting the focus

Traditionally, the emphasis has been placed on discovering ways to improve communication between a doctor and their patient. But the shift towards the inclusion of caregivers and other companions is a growing trend.

According to Jennifer Wolff, PhD, lead author of the Johns Hopkins study, caregivers who accompany their elderly loved ones to the doctor change the traditional dynamics of the patient-provider relationship.

In a separate analysis, Wolff and her colleagues

found that visits involving a companion generally lasted 20 percent (about five minutes) longer, and involved less dialogue between the patient and the doctor, and more dialogue between the companion and the doctor.

The caregiver companion's role during a physician visit is dependent on a variety of factors, including, how cognitively impaired an elderly loved one is, and what their specific health issues are.

Should you stay, or should you go?

In response to the question of whether or not a caregiver should attend the doctor with an elder who is physically capable of going on their own, Wolff says, "Absolutely." She points out that there is a significant amount of evidence indicating the benefits to having a companion sit in on a physician visit.

Doctor's appointments are often brief and abrupt, leaving a senior with little time to communicate symptoms, ask questions and comprehend a diagnosis. A caregiver can help their loved one with everything from prepping for a visit, to taking notes, to reminding an elder of a symptom that they may have forgotten to mention.

According to Wolff, research indicates that elders who were escorted to the doctor by someone else tended to be more satisfied with the overall care they received, and were more likely to remember important information after their visit.

Assembling and Managing a Loved One's Healthcare Team

Few decisions will have a greater impact on the quality of care that an aging adult receives than selecting the right medical professionals to oversee their healthcare needs.

As a caregiver, you will often be called upon to assume the role of team leader, making sure that your loved one's medical care crew is not only knowledgeable, but is also kept up-to-date on their ever-changing health status.

Does my loved one need a geriatrician?

Not every elder needs to see a geriatrician. However, these specialists can assist a family caregiver with managing the healthcare of an elderly loved one especially those who have multiple chronic conditions.

Geriatricians are doctors who have completed their residency in either Family or Internal Medicine, and have also undergone an additional one or two years of training in the medical, psychological and social issues of older adults. Their purpose is to provide primary care for aging adults, many of whom have complex medical conditions.

Geriatricians conduct health assessments, and are also responsible for developing a comprehensive care plan aimed at addressing an elder's various health concerns.

Choosing the right doctor or hospital

You may not always be able to pick which hospital your loved one is taken to or which doctors care for them.

But, when it comes to less immediate situations, such as scheduled surgeries and ongoing care, you and your loved one will be faced with some important decisions regarding which professionals you want to provide medical services.

Helping a family member select the hospital where they will undergo surgery, or the doctor who will oversee a course of treatment, can be a complex process.

How do you avoid "buyer's remorse" when searching for a reliable care provider?

Making these important decisions will require a little bit of research on the part of the caregiver.

Geriatricians are doctors who have completed their residency in either Family or Internal Medicine, and have undergone an additional one to two years of training in the medical, psychological and social issues of older adults.

Here are 5 Questions to Ask When Picking a Doctor or Hospital

1. Are they accredited or board certified?

This is the easiest way to tell whether a hospital or physician has met certain standards of care quality and safety. Hospital accreditation is administered by an independent accreditation body, such as the Joint Commission, and must be renewed on a regular basis. To become board-certified in a particular field (geriatrics, internal medicine, etc.) a physician must undergo additional training and examination in that specialty. To help with your search, MedlinePlus, an online resource from the National Library of Medicine, has a comprehensive [list of directories](#) for different types of healthcare providers.

2. Do they have the right experience?

Different providers have different areas of expertise. Is the doctor or hospital familiar with caring for people who have your loved one's condition? What is their track record with treating that particular ailment?

3. What are other people saying?

While the internet can be a good source of reviews and information on healthcare providers, don't neglect to seek the counsel of your friends and family. Do they have a doctor that they would recommend? Have they been (or do they know someone who was) hospitalized in that particular facility for a similar condition or procedure, with positive results?

4. Are they easy to talk to?

Having a good rapport with a medical professional is critical to receiving quality care. There needs to be a certain degree of 'chemistry' between doctor and patient (as well as between doctor and caregiver). Make sure that you and your loved one are comfortable communicating openly and honestly with a physician.

5. How accessible are they?

A caregiver's calendar can fill up fast, which is why it's important to make sure that your loved one's doctors have office hours that are compatible with your schedule. How far in advance do you have to make appointments? Does the doctor ever make house calls? How can the physician be reached in the event of an emergency?

How to Talk to a Loved One's Doctor

The average doctor's visit lasts approximately 15 minutes. Thus, there are two main rules of thumb when talking to a doctor:

- **Be honest** and upfront. Voice any questions or concerns that you may have.
- **Be brief** and strive to be as succinct as possible when voicing concerns and describing symptoms. Be respectful, but don't mince words.

Make the most out of a doctor's visit with a loved one by planning ahead:

- **Outline** the important information you wish to communicate.
- **Select several questions** you want to be sure to ask the physician.
- **Take notes** during each exchange with a doctor. That way, you won't have to worry about forgetting what they said, and you can refer to your notes if you have additional questions later on.

Guide to Managing Multiple Medications

The average older adult takes five or more prescription drugs each day, according to the Centers for Disease Control (CDC). Individuals aged 65 and older have double the risk of having to go the emergency room because of reactions to prescription drugs.

Being on too many medications – referred to as polypharmacy - can lead to potentially dangerous drug interactions and exposure to multiple drug side effects. Keep in mind, this applies not only to prescription medications, but also to over-the-counter medications and supplements.

Managing an elderly loved one's multiple medications is an essential step to protect them from the potentially undesirable side effects of polypharmacy.

Common symptoms of drug interactions include:

- Tiredness, sleepiness or decreased alertness
- Depression, or general lack of interest
- Constipation, diarrhea or [incontinence](#)
- Loss of appetite
- Confusion, either continuous or episodic
- [Falls](#)
- Skin rashes
- Weakness
- Anxiety or excitability
- Dizziness
- Hallucinations, such as seeing or hearing things
- Decreased sexual behavior

If you become concerned that your loved one might be suffering from the effects of polypharmacy, schedule an appointment with their doctor to discuss medications. Prior to the appointment, be sure to prepare a list of the medications (both prescription and over-the-counter) that your loved one is taking.

Information to Discuss With the Doctor

1. Any new (or unusual) symptoms.
2. What prescription medications they're on, including any changes in dosage or new prescriptions since your last visit.
3. Changes in an elder's daily routine, including deviations from the norm may indicate underlying health issues.

Vik Rajan, M.D., an AgingCare.com expert, offers

4 Questions to Ask to Avoid Polypharmacy in the Elderly

1. What all is my parent taking and why?
2. How necessary is each medication? Can any be removed?
3. Are any medications interacting with each other in a negative way?
4. Are any symptoms or conditions he or she is having potentially due to the medications themselves?

Additional Reading

AgingCare.com Articles:

- Knowing an Elder's Goals and Values Makes Health Decisions Easier [Read](#)
- What to Do If You Feel an Elder Is Being Over-Treated [Read](#)
- How Geriatric Care Managers Can Help Busy Caregivers [Read](#)
- What to do When an Elder Refuses to go to the Doctor [Read](#)

Questions and Discussions From Other Caregivers:

- How do you handle different doctors and nurses saying so many different things? [Read](#)
- How do I know when to let go when mom refuses to do what the doctors says? [Read](#)
- Mom doesn't remember to take all of her medications. What can I do? [Read](#)
- Should I be taking my husband to a neurologist, or a geriatrician? [Read](#)

On A Wing And A Prayer: Insights From Caregivers

“It is important to understand the levels of care and the costs associated with this care. Ask for copies of state inspection reports, inquire about the owners’ and sponsors’ long term financial stability.”

“Families and friends still need to be involved to “entertain” residents. Assisted living is just that... “assisted living” but not full time “we take care of absolutely everything.”

“The most rewarding thing is the relationship you will develop with your mom when she comes to live with you. Count yourself lucky to be able to have that. If it ever gets to the point that you need assistance there is a great deal available for the elderly so don’t fret. And if she deteriorates over the years and you have to put her in a facility even though you promised you won’t, don’t beat yourself up about it.”

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 5

Making Sense of Senior Housing Options

Helping an elderly loved one find the right place to live can be a formidable undertaking for caregivers and their families.

In this chapter, you will learn more about the different types of senior housing options available to aging adults, including the pros and cons of each choice, as well as important considerations to take into account while searching for the best place for your loved one to live. You will also receive a brief overview of how to pay for each type of senior housing through a combination of private funds and public assistance programs.

Articles in this chapter include:

- Breaking Down the Different Senior Housing Options
- Senior Housing Costs and Payment Options



Breaking Down the Different Senior Housing Options

Before examining the various senior housing categories, it's a good idea to list out all of the daily activities that your loved one needs help with. This will give you a jumping-off point which you can then use to select the best type of housing to fit those needs.

To find the right senior housing environment, take stock of your loved one's care needs.

Expect your elders to grieve their losses so that you aren't disappointed when they complain about the facility. Don't expect gratitude. For them, this move can be compared to a kind of death, so treat them with respect and don't rush them.

There are two main categories of daily activities with which aging adults typically need assistance

IADLs

Instrumental Activities of Daily Living

These activities deal with the day-to-day maintenance of a person's environment:

- Cooking
- Doing laundry
- Housekeeping
- Driving
- Financial management
- Medication management
- Using the telephone

BADLs

Basic Activities of Daily Living

These activities involve attending to a person's hygiene, mobility and bodily care needs:

- Bathing
- Dressing
- Toileting
- Eating
- Walking/getting up

5 Primary Senior Housing Options

Senior Housing	When This Works	Why it Might Not Work	Good to Know
Living at Home (“aging in place”)	<p>When elders prefer to remain at home, or with a close relative.</p> <p>Needed care can be provided by family member(s), or by hiring in-home assistance from a home care professional.</p>	Being the primary caregiver can put strain on not only the caregiver, but also family finances and interpersonal relationships.	Adult day care centers offer a broad range of activities and outings that can provide a welcome break for both the elder and the caregiver. Also, home health agencies employ aides who can be hired to come into your home and assist with IADLs, BADLs, or specialized medical care. Visit our Home Care section to learn more.
Independent Living	Aging adults who are ready to move to a senior living community - but can still care for themselves - will find freedom and socialization in Independent Living communities.	Some communities provide assistance with certain BADLs (transportation, light housekeeping), but most are unequipped to care for someone who needs extra help with bathing, dressing, etc.	Independent Living - also called retirement communities - offer various types of accommodations, from apartment-style living to free-standing homes. Learn more about Independent Living .
Assisted Living	Elders who require minimal assistance but who might not be able to live alone safely may find assisted living to be a good fit. Staff is available to help with IADLs and 24/7 medical professionals are on hand, in case needs escalate.	While staff will be looking out for your loved one when you’re not there, the tradeoff is likely to be a reduction in their overall sense of independence.	The cost of assisted living typically does not include assistance with IADLs or BADLs. These services are available, but they will add to the price. Be sure to ask upfront what’s included and what’s not. Our Assisted Living section will help you understand your loved one’s options.
Skilled Nursing Facility (SNF)	A SNF offers the highest level of care for elders, and is appropriate for those who have health conditions which require consistent monitoring and custodial care by medical professionals.	Your loved one may lose a great deal of their freedom and independence in an SNF. Family caregivers often struggle with the guilt of breaking the common pledge, “ I promised my parents I’d never put them in a nursing home. ”	Many skilled nursing homes are working hard to shed their negative image and change for the better. The next generation of long term care options aims to be more personable and person-focused.
Continuing Care Retirement Community (CCRC)	A relatively recent addition to the senior housing repertoire, the CCRC is designed to allow an elder to remain within the same community, but move into higher levels of care as their needs change.	The trickiest part about dealing with care in a CCRC is navigating complex models for pricing and government reimbursement.	The benefit of living in a CCRC is that your elderly loved one can more easily transition from one level of care to the next, without having to endure the stress of moving to a completely new environment. Doing your research and choosing the right community upfront can give your loved one the opportunity to age in a stable environment. Learn more about how to pick the right CCRC .

To find senior housing communities and services in your area, use the [Senior Living search tool](#).

Senior Housing Costs and Payment Options

As your loved one gets older, their care needs will change. At times these changes will be rapid, at times they will be slow. There are a wide range of senior housing options available to help your elderly loved one adapt to these changes. Knowing what the options are, what levels of care are offered (and at what price), and how to pay for care, will ensure that you and your loved one are optimally equipped to make the best decision regarding where they should live.

The Cost of Care and How to Cover It

The costs associated with taking care of an aging adult can be crushing to caregivers and their families. Even though some government assistance (Medicare, Medicaid, Veteran's benefits) may be available to help pay for senior housing and healthcare, it can be difficult to wade through the confusing mire of what these programs will and will not cover.

The following is a brief overview of the national average senior housing costs and payment options:

Living at home

The costs of caring for an aging adult at home will vary depending on the situation. For example, if you need to work during the day but your loved one needs consistent supervision, adult day services may be an option to pursue. In 2012, the average daily rate for adult day services in the United States was \$70, according to the MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs. Another option that can offer respite care for family caregivers is hiring a professional in-home caregiver. Home health aides provide basic healthcare services such as, wound dressing, bathing, medication disbursement and vital sign monitoring. Homemakers provide strictly non-medical assistance such as cooking, cleaning and socialization. Both categories of professional in-home caregivers charge around \$21 an hour. For a breakdown of the government programs available to help pay for professional in-home caregivers, see: [Paying for Home Care](#)

\$70 a day
The average rate for adult day services

\$21 an hour
The average cost of in-home care assistance

Independent Living

Independent living costs vary widely depending on the community, number of bedrooms in a particular apartment, and the care needs of the elders who are living there. Monthly costs can range from the low \$1,000s to \$4,000 and above. Because these costs are primarily living expenses and not medical-related, Medicare and Medicaid do not offer financial assistance to elderly adults living in independent living communities. Costs must be covered by the elder and their family via private pay funds.

\$1,000 to \$4,000
The average monthly cost of independent living

Assisted Living

One of the most often cited downsides to assisted living is that it is expensive. The average monthly rate for a room in an assisted living community in 2012 was \$3,300, according to AgingCare.com data collected from over 3,000 assisted living communities nationwide. Veterans benefits may help, and some medical-related expenses might be covered by Medicare or Medicaid. However, most assisted living costs must be paid directly by the resident or their family. While this figure may induce some initial sticker shock, many elders are surprised to learn that when they compare their current monthly costs (rent, groceries, utility bills, etc.) to the cost of living in assisted living, the rates can be quite comparable. The AgingCare.com [assisted living calculator](#) can help you compare your current monthly bills with the cost of assisted living in your area.

\$3,300

The average monthly cost of assisted living

Skilled Nursing

Skilled nursing care is typically the priciest form of elder care, due to the ongoing monitoring and medical assistance these facilities provide. The average monthly cost can be more than \$7,000, based on MetLife research that showed the average daily rate for a private room in a nursing home was \$248 in 2012; \$222 for a semi-private room. Government programs do provide financial assistance for elders in need of skilled nursing care. Short-term care at a skilled nursing facility (100 days, or less) is covered by Medicare. In order to receive financial assistance to pay for a longer stay, an elder must qualify for Medicaid.

\$7,000+

The average monthly cost of staying in a skilled nursing home (\$222 to \$248 per day)

Making Sense of Senior Housing Dollars and Cents

Senior housing costs can eat into an aging adult's monthly budget in a dramatic fashion. It's vitally important that you take the time to educate yourself and your loved one about all of the available options for care and financial assistance.

With that knowledge in hand, you'll be able to confidently decide where your loved one will receive the care that fits their individual needs--and come up with a strategy to pay for it.

To help you compare your loved one's current living expenses to the cost of living in senior housing, consult our [assisted living calculator](#).

Assisted Living Calculator

The AgingCare.com calculator will help you compare current home costs to the estimated cost of assisted living. In just 3 steps, our calculator will help you determine how much you can afford to pay for assisted living. Get Started!

STEP 1 Getting Started | **STEP 2** Monthly Income | **STEP 3** Monthly Expenses | Your Results

Step 3: Estimated Monthly Expenses

Please estimate your Mother's current existing living expenses. National averages are presented ONLY AS A GUIDE to help you estimate your own monthly expenses.

Rent / Mortgage	\$ <input type="text"/>	Rent or mortgage should include costs associated with the dwelling. When estimating your monthly expense, consider the following: National averages are shown. Adjust with your own estimates as needed.
Utilities	\$ <input type="text"/>	
Food / Groceries	\$ <input type="text"/>	
Household	\$ <input type="text"/>	
Automobile	\$ <input type="text"/>	
Entertainment	\$ <input type="text"/>	
Est. Monthly Expenses	\$ <input type="text"/>	

Rent / Mortgage	\$ 1,008
Property Insurance	\$ 69
Real Estate Taxes	\$ 90
Association Fees	\$ <input type="text"/>
Total	\$ 1,167

[Click to apply total](#)

Additional Reading

AgingCare.com Articles:

- Visit our comprehensive guide on Assisted Living [Read](#)
- Living With Elderly Parents: Do You Regret the Decision? [Read](#)
- 7 Tips to Avoid the Biggest Mistake People Make When Choosing a Nursing Home [Read](#)
- 10 Myths About Home Care for Elders [Read](#)

Questions and Discussions From Other Caregivers:

- What should I consider before deciding if my aging parent should move in with me? [Read](#)
- How do you know when it's time to place a loved one in assisted living or nursing home? [Read](#)
- Does anyone have any positive experience with assisted living centers? [Read](#)
- How can I change my mother's nursing home if she's unhappy? [Read](#)

On A Wing And A Prayer: Insights From Caregivers

“If anyone has the opportunity to give yourself a break, do it. It will make things easier in the long run. I had 5 days of respite and it was so wonderful to sleep for one whole night. I woke up so refreshed. Mom adjusted fine and was sleeping when I left. I checked on her, but also enjoyed my rest.”

“You have to decide how long you can be the caregiver. Some caregivers try but they don’t have what it takes. I was one of those. After 3 years it took its toll on me and I had to turn the care over to others.”

“Since reading and writing on the AgingCare forum, I have moved from guilt to anger to a quieter, more peaceful and stronger place in such a short period of time - a matter of weeks. I feel so grateful for this forum for the help it has been to me.”

- Members from the
AgingCare.com Forum

Agingcare.com

Chapter 6

Caring for Yourself While Caring for Family

Family caregivers must make their own physical, mental and emotional health a priority. It may seem counter-intuitive to the newly-minted caregiver, but an elder’s health and wellbeing is intimately tied to their caregiver’s health and wellbeing.

In this chapter, you will learn how to avoid being defined by your role as a caregiver, discover strategies for managing stress and difficult emotions and uncover vital sources of support you may not even realize you had access to.

Articles in this chapter include:

- How to Avoid Being Defined by Your Role as a Caregiver
- Caregiver Stress: What it is, and How to Handle It
- How to Honor Your Needs While Caring for a Loved One
- Why Caregiving Must be a Team Effort



How to Avoid Being Defined by Your Role as a Caregiver

Caregiving: a verb, not a definition. It should be easy for a caregiver to see themselves as a verb—after all, they're always doing something.

People taking care of an older relative constantly bounce between dozens of daily tasks: driving an elder to their doctor's appointments, cooking dinner, working a day job, making sure a loved one takes their pills.

A caregiver herself, author and columnist Janice Taylor knows how exhausting it can be just to make simple everyday decisions for her mother. What should she eat for dinner? Which of her outfits should be kept and which should be thrown away?

When faced with this never-ending series of tasks, a person's sense of self is often the first thing that gets sacrificed.

Taylor explains that it can be challenging for people taking care of elderly parents to connect with their true selves. "Society tells you what you're supposed to do and how you're supposed to feel," she says, "We're bad people if we don't drive ourselves mad and go deeply into caregiving."

The wisdom in cliché advice

Set boundaries. Put on your own oxygen mask first. Ask for help.

These statements are the cornerstones of the informal caregiver creed. They also highlight the vital importance of staying true to yourself while taking care of another human being.

Before you can set meaningful boundaries with a loved one, you must decide how much you're willing to give. Before you can ask others for help, you must first be able to recognize (and accept) that you've reached the end of your proverbial rope.

"It's okay to express that you're completely overwhelmed," Taylor says, "You need to define your role as a caregiver and know how much you're comfortable with, based on your own sense of self."

Know yourself. Know your feelings and your limits and don't be afraid to voice them.

Who Are You?

Three words; so simple to read, so difficult to understand.

"We are not defined by one role. We think of ourselves as nouns – but we are really verbs. We are beings."

— Janice Taylor, author, columnist and life coach for Virtual Shoulder.com

Here's how AgingCare.com members answered the question: Who are you?

“ I am also a girlfriend, along with being a mother to my grown children, a sister, an aunt, a friend. Sadly, I don't think of myself so much as a daughter anymore, but a caregiver.”

“ I am also a yoga teacher, a volunteer, a confidante, an herbalist, and I need to remember that!”

“ I am a dancer who paints, weaves beads, and has a Masters in astrophysics.”

“ I am in fact a caregiver who is also a writer. I view my writing time as a release from my care giving duties.”

“ **Most of all, I think that we are fighters; fighting for those we care for, and for ourselves too... to do what is right today and to survive to fight another day.**”

Portrait of a whole person

How do you learn to temporarily subtract the caregiver title from your resume and tap into who you really are?

It can be tricky, particularly if you've been looking after a loved one for years. Taylor offers some advice for re-connecting with and getting to know your true self:

Engage your core

Think about your core set of inner resources. Define yourself by the things you like to do, not by your relationships to other people. For example, you may be a creative person who enjoys writing, singing and practicing yoga.

Talk about yourself

Engaging in third-person self-talk can help you come up with alternative definitions of who you are. For example, you could say to yourself, "(Your name) is a quilter, attorney and an unabashed romance novel nerd." Taylor says this method, "puts you in a place where your mind isn't hijacked by what's going on, where you're more than your thoughts."

Connect under the covers

Re-tooling your self-definition doesn't mean that you have to spend hours sitting alone, meditating on the mysteries of life. Taylor suggests taking a few minutes right after you wake up in the morning to connect with your

inner being. "Remember who you are before you get out of bed," she says.

Talk to strangers

There's perhaps no better way to re-invent yourself than by being around people you've never met before. Look for groups and clubs in your area that are focused on the things you're interested in. This will enable you to explore a personal passion, while introducing you to people who have no pre-conceived opinions about who you are. Conversing with strangers can offer a refreshing change of pace if your day-to-day interactions constantly seem to revolve around one question: "How's mom doing today?"

Set some goals

Most people tend to shelve their own ambitions once they start looking after an elderly loved one. But, setting personal goals can be a great way to explore and re-ignite your passions. According to Taylor, the most important aspect of goal setting is consistency. Take ten minutes each day to work towards your target, whether it's writing the next great American mystery novel or growing an herb garden in your backyard.

Looking for more inspiration and advice to help you plug in to your true self while caring for a loved one? Check out the discussion: "[More than just a caregiver...](#)"

"I've started to focus on just doing my best—sometimes that means being real and honest about what I need."

— AgingCare.com member

"All thinking is a habit. Never get so wrapped up in trying to fix the unfixable things that you forget that your soul has a purpose."

— AgingCare.com member

Caregiver Stress: What it is, and How to Handle It

Individuals who are responsible for taking care of an elderly loved one often encounter high levels of stress and anxiety. When experienced over a long period of time, these emotions can have a distinctly negative impact on their overall health and wellbeing.

People who suffer from caregiving-related stress have a 63% increase in their mortality rate, according to a 2003 study, conducted by Ohio State University.

If you feel overwhelmed and find yourself experiencing several of the symptoms highlighted on the right, then it may be time to re-evaluate your approach to stress management.

63% is the increase in mortality rate for people who suffer from caregiving-related stress.

— Research by Ohio State University

10 Common Symptoms of Caregiver Stress

1. Depression
2. Withdrawal
3. Insomnia
4. Trouble concentrating
5. Anger
6. Health issues
7. Exhaustion
8. Anxiety
9. Drinking or smoking
10. Altered eating habits

The following 10 strategies can help you keep a lid on caregiver stress:

1. Prioritize your to-do list and establish a daily routine to get things done.
2. Say “no” to social requests that are draining or stressful (i.e. hosting holiday get-togethers).
3. Set realistic goals and achieve them by breaking up large tasks into small, do-able chunks.
4. Try to maintain a sense of [laughter and humor](#) while caregiving.
5. Set aside time for yourself; [make time for happiness](#).
6. Keep in touch with family and friends.
7. See your doctor for regular health checkups.
8. Consider professional counseling to deal with difficult emotions, including grief and guilt.
9. Forgive yourself for being less-than-perfect.
10. Don't forget to ask for help from family, friends, support groups and your local Area Agency on Aging.

For additional information on coping with stress, avoiding burnout and maintaining your sanity while taking care of an elderly loved one, consult this collection of [caregiver support articles](#).

How to Honor Your Own Needs While Caring for a Loved One

Why is it so hard for a caregiver to switch into “me” mode?

Caregivers are constantly being told that they need to find a way to take time for themselves, whether it be looking for respite care, taking their loved ones to an adult day center, or just getting out of the house and going for a walk.

But, for a person who is used to taking care of someone else, finding the time to unwind is often easier than actually being able to let go and relax.

Cindy Laverty, caregiver coach, radio talk show host, and author of “Caregiving: Eldercare Made Clear and Simple,” experienced this dilemma first-hand when she became the primary caregiver for her ex-husband’s father and mother.

Laverty says that she became so consumed with the need to remain in control and take care of everything in her in-laws’ lives, that she neglected to take care of herself in the beginning stages of her caregiving journey. This led to a brush with extreme caregiver burnout, as well as a resolve to re-think her approach to caregiving.

According to Laverty, there are certain thoughts that can inhibit a family caregiver’s ability to calm down.

These thoughts form the foundation of an internal monologue that convinces many caregivers that they are the only ones who can provide adequate care for their loved one.

However, as Laverty points out, this is not the reality. “While an outside caregiver is not going to do caregiving the way the primary caregiver does, that’s okay, as long as the person is cared for,” she says.

What Prevents You From Letting Go?

“I need to be in charge of everything that has to do with my loved one’s care.”

People assume the role of caregiver and think that they can do everything for six months, but, in this world, that role can last for years, even decades. You can’t be in charge of everything.

“I can’t stop worrying that something will go wrong if I’m not there.”

Some caregivers, when offered the opportunity to take a breather, find that they can’t stop their minds from running through dozens of “What if...?” scenarios. What if my mother falls and the respite caregiver can’t pick her up? What if my father has another stroke while I’m gone? These kinds of thoughts can make a caregiver incapable of relaxing, even when they’re away from the person they’re caring for.

“I shouldn’t be enjoying myself while my loved one needs care.”

Guilt can make a caregiver feel as though they’re being selfish by taking some time for themselves. A guilt-ridden caregiver who does decide to take some time away may become so consumed by regret that it’s impossible to relax.

— Cindy Laverty

Laverty offers some tips to help caregivers cope with these thoughts and learn how to let go:

Make the decision that your life matters

Because they are so consumed by caring for their loved ones, caregivers are notoriously bad at taking care of themselves. The only way to get rid of this obsessive, “on call,” mentality is to decide that you matter just as much as your loved one does. It won’t be easy, but realizing that you, the caregiver, deserve to have peace and tranquility is the first step towards being able to make the most of your time away from a loved one.

Ask for help, more than once

A common caregiver lament is that it’s hard to find anyone who will help out. When caregivers tell Laverty that their family/friends refuse to assist them, she replies, “When was the last time you asked?” It’s true that some people may not be able to shoulder a significant portion of the caregiving burden, but Laverty says that an important part of asking for help is accepting how your friends and family show up. For example, your sister may not be able to help you with the day-to-day care of your mother, but she might be able to cook a week’s worth of meals for you—this is how she is showing up to help. If you demonstrate your appreciation for the assistance that others give, no matter how seemingly insignificant, it can make them more

likely to look for other ways to help you in the future.

Decide to really be “gone”

Being “gone” means that, barring an emergency, you completely remove yourself from the situation of being at your loved one’s beck and call. Making the decision to relax and truly be gone can be extremely difficult for a caregiver. Laverty attributes the trickiness of this endeavor to the fact that a caregiver’s mind is constantly in “fix-it” mode. When you’re taking care of an elderly loved one, it can be hard to accept that you often can’t “fix” what’s causing them pain. What you can do is help make them happier, healthier, and more comfortable. “When you stop trying to fix everything, it gets so much easier to relax,” says Laverty.

When you have time, do something you enjoy

The key to successful relaxation, according to Laverty, is doing things that bring joy back into your life. This will mean different things for different people. For some, it might be taking a hike with a good friend. For others, it could be getting a manicure or a massage. “When you’re engaging in joyful activities for yourself, it’s hard to stay stuck in the ‘What if’s,’” Laverty says.

Learning how to let go is likely to be a difficult process for those who are taking care of an elderly loved one.

Laverty cautions that being alone with your thoughts may not be a pleasant experience, especially in the beginning. Ugly, scary emotions are likely to surface, but they have to in order for you to find peace. She suggests therapy, journaling and meditation as a few ways to help you cope with these difficult feelings.

Ultimately, true relaxation is about discovering how to connect with (and love) yourself—warts and all. “Caregivers need to learn how to be easier on themselves. You don’t have to be perfect,” Laverty says.

If you find that your caregiver guilt is provoked by this notion, Laverty recommends quelling it by asking yourself this simple question: *Why are you more into caregiving than you are into having joy, peace and serenity?*

Why Caregiving Must Be a Team Effort

You've probably heard the old saying, "there's no I in team," meaning that on a team everyone works together toward a common goal.

Unfortunately there is an "I" in caregiving and that "I" can represent many challenges that caregivers face daily: Isolation. Infuriating. Irritating. Imperfection. And at times, seemingly Impossible.

During my years of caregiving, one incident in particular made me realize that in order for caregivers to keep their sanity, they have to eliminate that "I" by building a support team.

What happened that led to my epiphany?

One cold winter day years ago, Julie, my mail carrier, knocked on my door much earlier than she'd normally pass by my home. Julie had been delivering the mail on her route a couple of blocks over when she noticed movement behind the snow-banked sidewalk across the street. Thinking it may be an injured animal, she investigated.

What she discovered was my 80-year-old neighbor, Joe, crawling toward home. Joe had taken off on one of his impulsive walks to an old downtown tavern without considering the lack of sure footing. On a good day, with dry cement under his feet, Joe shuffled with an occasional sideways wobble. Put ice and snow underfoot and his walk was an invitation for disaster. Miraculously, Joe was cold but unharmed, except that he couldn't get back on his feet. Julie helped him up and took him home, then came looking for me, since she knew I was his primary caregiver.

As Joe's caregiver, I expressed my gratitude to Julie, then went next door to Joe's house and spent a fair amount of time scolding him. He

knew I'd give him a ride wherever he wanted to go, and he could afford a taxi when he chose to be independent. Joe responded with his characteristic shrug. He stubbornly ignored my advice.

I developed a new awareness and gratitude that day for people like Julie who are part of our elders' regular routine. Postal carriers have been known to call the police when they see too much mail piling up in someone's box. UPS and Fed-Ex delivery people, as well as others who run routes, have been known to find assistance for people when they notice something amiss. People who deliver Meals On Wheels are trained to watch for signs that something is wrong in the world of their meal recipients. All of these routine delivery folks are, often unknowingly, part of an elderly care team.

During my two decades of caregiving for multiple elders, I was the primary person responsible to look after my elders' needs. Whether it was for emergencies, shopping, medical appointments, medications or handling complaints, I was there. However, within the framework of my care, there were many others who helped me and my care receivers. There was always a care team, albeit an ever changing one, depending on the elders' needs.

"Caregivers learn quickly who actually cares. And, more importantly, they learn how to survive without the people they thought cared."

— AgingCare.com member

Creating Your Care Team

Family Members

When willing, family members are the obvious backup for the primary caregiver. Some families share the care, while others do their best to distance themselves from any family caregiving. Give willing family members a chance to contribute when they can.

Often people feel overwhelmed by care needs, or simply don't know what kind of care to offer, so they do nothing. It may help if you, as the primary caregiver, can ask for a specific task. Here's some additional information on [getting your siblings to help with caregiving](#).

Friends

Your close friends can also help. True, some "friends" may disappear when a family becomes shouldered with responsibility due to an ill loved one. However, as with family members, give friends a chance to help without the threat of taking over their lives. You can request a certain favor and see how the request is received. You don't want to wear out your friends, so ask for help sparingly. Distant friends can also be part of your unofficial team: long-time friends, neighbors who may notice something "off" about a senior's routine, senior center friends and church groups.

Medical Professionals

Having a variety of medical professionals helping our elders means that there are more people to suggest helpful changes in care plans. Potential helpers include: the primary physician, a physical and/or mental therapist, nurses, CNAs, social workers or others.

Treat doctors, nurses, aides at facilities, social workers and other professionals with respect and courtesy. Ask for advice when appropriate. If you consider them part of the care team when you are at home with your loved one, then they are more likely to welcome you to the care team if your elder needs facility care later on.

Other Caregivers

Other family caregivers can be amazingly helpful. Whether we find them at a local support group, meet them while visiting loved ones in the nursing home, or connect with them in an online [caregiver forum](#), like AgingCare.com, you can receive insightful support from others in similar situations.

Government Resources

Visit your state's website (usually found by typing your state's name followed by .gov in your computer search engine, i.e. Florida.gov). Once there, search under words such as "aging", "department on aging" and "caregiving". By doing so, you should find an abundance of links leading you to local assistance. This assistance can range from government programs such as your Area Agency on Aging to local respite care and caregiver support groups. The people you contact through these links may lead to others who will eventually become part of your growing care team.

If you broaden your thinking and do some research you can become educated in available resources. By touching base with different groups and agencies, you should find that you needn't handle everything alone.

Additional Reading

AgingCare.com Articles:

- Caregiver Strong: Reviving and Harnessing Your Personal Talents [Read](#)
- Feel at Peace: Lose the Caregiver Guilt [Read](#)
- How to Stop Being So Hard on Yourself [Read](#)
- 7 Ways Caregivers Can Make Time for Happiness [Read](#)

Questions and Discussions From Other Caregivers:

- Is caring for elderly parents harder than caring for children? [Read](#)
- I don't want to be mom's caregiver. Why do I feel this way? [Read](#)
- How can I get beyond the feelings of loneliness while caregiving? [Read](#)
- Are there any positive caregiver success stories out there? [Read](#)



Chapter 7

Questions You Never Thought You'd Have to Ask

Taking care of an elderly loved one will inevitably bring up a multitude of questions. Oftentimes, these questions will deal with issues that you won't feel comfortable discussing with anyone—even your best friend, or closest family member.

The ideal people to offer guidance in these circumstances are the nation's 65 million family caregivers—those who've seen it all, done it all, felt it all, and are willing to share it all.

In this chapter, you will discover ten questions you never thought you'd have to ask, and will learn what caregivers and elder care experts have to say about each one.

Articles in this chapter include:

- 10 Questions You Never Thought You'd Have to Ask

10 Questions You Never Thought You'd Have to Ask

It's an unavoidable truth of caregiving that, somewhere along the way, you'll come across issues and encounter questions that you wouldn't feel comfortable talking about with anyone—not even a close confidant, or a best friend.

Where do you go for help when you find yourself in this situation?

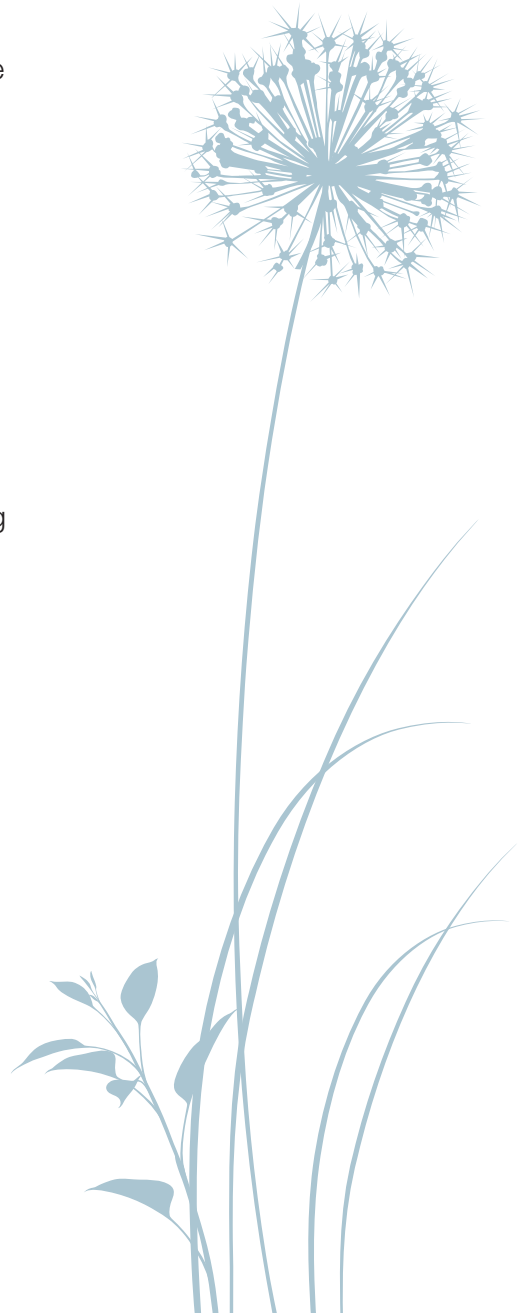
When aiming to uncover information about any topic it's always best to consult prominent experts in the field.

For family caregivers, this means not only seeking guidance from professional elder care experts (doctors, nurses, financial planners, etc.), but also turning to one another to find support, encouragement and useful insights on how to handle caregiving's most awkward moments.

After all, who knows more about what it means to be a caregiver than caregivers themselves?

Local support groups and online caregiver communities (such as AgingCare.com's Caregiver Forum) can connect you with knowledgeable subject matter experts, as well as other family caregivers who know exactly what you're going through and who can provide invaluable insight on dealing with caregiving's most bizarre issues.

We've compiled our "Top Ten" most awkward questions you may encounter, followed by practical advice from our **Caregivers** and our **Experts**.



1. What can I do about Dad's body odor? He won't shower.

Caregiver: Repetition: don't overlook the possibility that your loved one can't remember the some of the details of HOW to perform self-care.

Caregiver: My mother-in-law used to give herself a sponge bath at the kitchen sink (highly ineffective). Turned out she was afraid of falling in the bathtub and that is why she never took a shower. So my husband and I took off her shower door and put up a curtain. Then we put in a shower bench that has two legs that go outside the tub, and two that are inside the tub. There was already a shower wand instead of the typical shower head installed. She had a cow that now we were expecting her to take a shower, but I made her practice first, fully clothed to get used to the idea. Now she takes a shower all the time (but still won't wash her hair herself).

Caregiver: Here's some advice an expert gave me - "get a prescription for a bath from the doctor," she said. "Never fails." My aunt's doctor obligingly wrote a prescription ("patient is to bathe once a week") and gave it to her.

2. Dad refuses to wear adult diapers and continues to walk around leaking urine like it's no big deal. What can I do?

Expert: Try getting an old friend (or his doctor, if all else fails) to get him to understand that smelling like urine is not "independence," taking care of the problem is! I know it's hard, since most adults have trouble accepting incontinence issues. Family members are often considered "nags." But a third party can sometimes get through. If he realizes a friend notices the problem, he may do something about it. (Learn how to [choose the right adult diaper](#))

The Brighter Moments

shared by
AgingCare.com members

"Grandma's community had a hat party. She didn't have a hat, so she went wearing a pair of lace panties on her head. You're never too old to have fun."

"They told me that mom got lots of exercise yesterday – she was happily walking the halls for hours. Turns out, she was lost and couldn't find her room, but didn't tell anyone! She just walked around smiling at everyone."

3. My elderly mother is falling more often. Can it be from her medications?

Expert: Yes, definitely. Medications are the single biggest reason seniors experience falls each year and are the number one preventable accident experienced by seniors. Falls are serious because they are the leading event that causes declines in the health of seniors. A large majority of seniors experience a second fall within six months because the causes of fall are not addressed. Again, medications are the single biggest reason seniors fall each year.

4. What do I do when my mom with dementia thinks the people in pictures are real – and she waves to them?

Caregiver: My mother has dementia and has the same symptoms. She thinks photos are alive and the people on television can see her. I have had to turn off the TV when she is changing her clothes! I try to explain to her that they are not real people—just pictures—but this is how her mind is working. Just be patient and go along with it. It's not worth upsetting her and frustrating yourself constantly.

Caregiver: I once told her, when she was waving, to stop because it was embarrassing me. She got mad and said, "No one lets me do what I want to." Then, she went around to each picture and said, "I can't wave at you anymore." Well, that didn't happen. The next time we were there, she just waved and even dances for them.

Expert: My client also thought pictures were real and the television stuff was actually happening in the lounge. She could get very upset by it though, so I was constantly vigilant and ready to switch it off in a second. At least your mom seems to find it a pleasurable experience to interact with these images and seems happy. It is embarrassing; but go along with it. Try to be glad she is happy; never mind what people think.

The Brighter Moments

shared by
AgingCare.com members

“When the EMTs came, mom looked around, smiled and said, “I have never had this many men in my bedroom in my life!”

“Our cat, Sam, has been acting weird and we couldn't figure out why – until yesterday – when my sister caught Mom putting coffee in his food dish.”

“Mom fell asleep reading the paper. When I told her, she said, ‘No, that was just a really long blink.’”

5. How do you give a bed bath?

Caregiver: If I were you, I'd call a local home health company and ask that they send their most experienced aid out to show you the most effective and safe way to do this.

Caregiver: I used to wash mom's bottom half while she was still in bed. You can get no rinse bath wash and shampoos at most local pharmacies. Or, you can put warm water in a bowl and do it that way with soap and water. Just do one side and turn her over and do the other. And while she was up in her wheelchair I would do the top half and hair. The no-rinse shampoo is not great, but it can be a life saver.

Caregiver: I give my mother a bath every morning in her bed. I bring a bucket of water, a wash cloth, sponge and hand towel. I first sit her up in bed and take her nightgown off and put soft soap on the sponge and do her back, rinse off with the wash cloth and dry her back. She then lies back down and I do her legs and give her the sponge to wash her face, arms, upper torso and private while I rinse and dry her legs and feet. Then she turns on her side and I wash her bottom. Then we put deodorant and powder on and get dressed.

6. How do I dispose of mom's diapers so they don't stink up the house?

Caregiver: Get a large plastic bucket of kitty litter and empty litter into another container. These buckets are sturdy and have secure tops. Line with two sturdy plastic bags. Put kitty litter into the bottom of the bag. Place dirty diaper face down, then pour on more litter as needed, add any soiled paper towels, latex gloves, etc. Add more litter to cover messy stuff (perhaps enough to place next diaper face down into the litter). Layer the soiled diapers and kitty litter until the bag is full, adding more litter if the box is smelly. Between uses, twist the inner plastic bag closed, and put on the lid. When the bucket or box is full, twist inner bag closed with twisty tie, add some baking soda for more odor control. When bucket or box is full, seal up, perhaps mark "SOILED DIAPERS!!" on it and dispose in garbage can.

The Brighter Moments

shared by
AgingCare.com members

"I asked mom if she wanted the TV on. She said no, she wanted to listen to the quiet and think about her life. What a great reminder to turn off the noise and allow space for our good thoughts."

"Don't forget to ask for help. The more you search for it, the more you'll find."

"One evening my parents were watching TV when my dad look over at my mom and said, 'Are you ever going to go home, you've been here all day?'"

7. How do you handle inappropriate sexual behaviors or conversations with an elder?

Expert: Many people with dementia can get into inappropriate sexual conversation because they've lost their inhibitions or they simply don't understand what they are doing. Try to distract the person with other things, such as an old photo album with recognizable (to that person) people, or music or a DVD of old TV shows the person may remember. Getting the person's mind off of their current obsession can help diffuse these uncomfortable encounters. Try to ignore any inappropriate comments as you re-direct their attention.

Caregiver: I went through that with my father-in-law after mom in law died. It started with inappropriate jokes and worsened. You might try going to see him, waiting for him to be inappropriate (shouldn't take long, and try to make it happen in front of witnesses) and tell him straight out that if he intends to remain a valued member of the family, he MUST clean up his act. Tell him frankly that his family members are disgusted by his behavior and he must keep it away from the family, period. Age is not an excuse for rudeness. Dementia is one thing, but if it's not dementia, there's no way you or anyone else should have to put up with that 'dirty old man' behavior.



The Brighter Moments

shared by
AgingCare.com members

“Helping my husband get ready for bed, I said, “Let’s get into these pj’s now.” He replied, “Well, I’m willing to try, but I really don’t think we’ll both fit.”

“My mother-in-law moved into a nice dementia unit. When we visited for the first time, I introduced myself as Bob. The whole place started laughing because every time she did something wrong, she told them ‘Bob did it.’ She still blames me for everything!”

8. What can I do about my parent's filthy house when they refuse to let me clean?

Caregiver: I suggest you take your mother away from the house for the day. Then clean up the areas that need it the most. Don't throw away items she may ask about, but discard anything that is considered trash. If it is filthy to the point of being unsafe, you may want to report it to a social worker or the Department of Children & Family Services. They will send someone out to the home to determine if there is an unsafe and unclean home, and then make the family take action.

Caregiver: If hoarding is involved, the longer you wait the worse it is. My mom had boxes and piles of stuff up to the ceiling. The basement was stuffed full and most of the boxed items were junk. She had jars of plastic water bottle caps safe on the high shelves and precious family stuff on the floor where they got wet. Try to move the stuff out of there when she isn't there. Tell her you're putting it in storage and it all is safe and sound, but it can't be in the house anymore. There is a happy ending! Mom loves what we did with her house. It's all fixed up, and she knows that her stuff is safe. I saved the good stuff, showed her those and she was satisfied.

Caregiver: Maybe it's time for your siblings to come and get their childhood stuff? If you can't convince your siblings to get it together, maybe you need an attorney simply to protect your parents from the consequences of their actions and their children's inactions. The filth really gets in the way of everybody's quality of life. Take a video and show your siblings how bad it is.

The Brighter Moments

shared by
AgingCare.com members

"Mom told the doctor she was 44 years old. He asked me how old I was, I told him 63. Mom turned to me and asked, "How did you get that old?"

"The restaurant had a "free wi-fi" sign. Mom looks at me, totally serious, and asks, "I wonder if we can get some of that "wee-fee" to go."

"You have to make peace with the changes and learn how to love them as they are now."



9. What if I think my dad is an unsafe driver; should I report him?

Expert: Getting older doesn't make your elderly parent a bad driver. But there are changes that may affect driving skills over time, including: vision and hearing impairment, slower reaction time, certain health conditions and medication side effects. Do they get lost frequently? Do other drivers honk at them? Do they have trouble staying in their own lane? If so, it might be time for them to give up the keys.

Caregiver: If you do not feel (your father) is safe, call the DMV and they will probably have him take a road test which he will not be able to pass.

Caregiver: I had a very stubborn mother and finally used the direct approach. "Mom do you think you should be driving anymore, it scares me to get in the car with you and I'm afraid you're going to hurt/kill someone." She handed the keys straight over.

Caregiver: My Mom was resistant and these are the steps we had to take, recommended by Elder Services:

- Mom's doctor told her in person - absolutely no more driving and why.
- We had to have the doctor call her several times and put it in writing
- Next the doctor contacted DMV and had her license revoked
- Meanwhile, we had to disconnect the battery and take her keys away

I had recently been to my own doctor shortly before this and the nurse told me that morning that an elderly person with impairments had hit and killed a police officer on detail at a construction site. He left three small children. So, I knew what we had to do, no matter what.

The Brighter Moments

shared by
AgingCare.com members

"Mom and I were in the car. "Do you think I'm crazy?" she asked me. We both looked at one another and, at the same time, said, "Not yet!"

"Mom is a different person now, but sometimes the old 'dragon' manages to peek through and makes me smile."

My mom is only 4'6 and she runs the hallways in her Geri Chair. She keeps them hopping, and for 84, she can really go! That's my momma!

10. How do I deal with taking my dad to a public men's bathroom as a female?

Caregiver: I took my dad who had Alzheimer's/incontinence several times into women's restrooms. I just smiled at the women in there and most were very understanding. It is better when there is a family restroom but that's not always possible. I put two adult diapers on him when we went out, an incontinence pad for the seat in the car, a bag with extra adult diapers, latex gloves, wet wipes and a change of pants/underwear. Trust me you get used to it after a while.

Caregiver: I carried a post-it note in my purse to put on the outside of the ladies' restroom door to let other women know that I had my husband with dementia in the restroom with me. Everyone was very understanding about it. As we left the restroom, I just took the post-it off the door and put it back in my purse for the next time.

Caregiver: Take him to the women's restroom. You will feel the most awkward about the situation. I believe that you walking in with an elderly man and escorting him to the restroom is basically understood by most of us as to what the situation is. There are stalls that give everyone privacy. I give you a big hug for continuing to take your father places. So when you take your dad into the restroom hold your head high do not feel embarrassed. You are a wonderful daughter for taking such good care of dad.

Caregiver: As a man, if you brought your father into the men's room I'm sure that men might offer to help or would clear out to give you privacy. If you had to go into the men's room maybe ask a security guard to help. I am in the reverse situation - I'm male and the sole caregiver for my mother who is in a transport chair. It is difficult to travel or go to the department store at Christmas, which she would love to do. We've managed somehow. Once a woman helped her - a total stranger. I almost cried -there are angels out there.Of course, no amount of helpful information and outside support can change the fact that taking care of an elderly loved one is profoundly challenging and will force you to adapt in ways you never thought you would have to.

The Brighter Moments

shared by
AgingCare.com members

“As individuals, we experience different obstacles. Yet ultimately all caregivers walk a similar path.”

I took my mom to a reunion in France. When we arrived she went to bed and didn't get up for three days. I brought her meals, and finally begged her to get up, telling her that she was wasting her time in Paris. She said “But darling, I sleep so well in Paris!”

No matter how long your caregiving journey lasts you will likely experience the full range of human emotion many times over. Learning how to ride the highs and lows is ultimately something that each individual caregiver must figure out for themselves.

Hopefully this guide has provided you with some additional knowledge to help you progress more smoothly down the caregiver's path.

AgingCare.com exists as a consistently-updated online resource for people taking care of elderly loved ones; offering information, inspiration and connection to the millions of family caregivers in need of succor and support.

As one of our members so aptly phrases it, "You're not alone. Always remember that there are many of us out there—and we are ALL pulling for you."

About AgingCare.com

AgingCare.com exists to fulfill one simple yet critical mission: to provide free information and support to help those caring for elderly family members.

Our aging population means that the demand for caregivers will continue to rise. As family members step into this role, we are committed to being the trusted resource that they can rely on to make informed decisions and ease the stress of caregiving.

AgingCare.com is the go-to destination for family caregivers, providing trusted information, practical answers to real-life questions, and ongoing support through every challenge.