How to Care for Aging Parents

A One-Stop Resource for All Your Medical, Financial, Housing, and Emotional Issues

Indispensable!
— AARP

The bible of eldercare.
— ABC World News

3rd Edition
Completely Revised and Expanded

PREVIEW ONLY
How to Care for Aging Parents

A One-Stop Resource for All Your Medical, Financial, Housing, and Emotional Issues

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WORKMAN PUBLISHING • NEW YORK
Chapter 1

First Things First

Ten Survival Tips • Critical Conversations • Gathering Vital Documents • Exploring the Options • Getting Organized • When You Can’t Be There

Most of us don’t plan to take care of a parent. We don’t set aside time or money for the task, or factor it in when thinking about retirement. For the most part, a parent’s old age, and the needs and dilemmas that typically accompany it, seem to come out of nowhere.

The transition can come with a jolt—after a fall, a stroke, or a diagnosis—but more often than not the demands of parentcare slide slowly into our lives. Dad is a little hunched over, his step wobbly. Mom left the stove on and burned a pot. Again. The car has a new dent. Pill bottles line the sink.

Even then, some part of us clings to the hope that our parents will be all right and our services will not be needed. But with time come housing issues, money problems, medical complications, and questions, so many questions. How do we stop her from driving? Is he eating properly? Can she be left alone? Who will take him to his doctor’s appointment? Is that a new symptom? Will insurance cover this?
We don’t plan for it, but at some point we are in it, solving each crisis only to find another in its wake. We muddle through, day by day, juggling their lives, and ours.

No matter where you are in the process—whether you’re just starting out, deeply enmeshed, or nearing the end—the most important thing you can do for your parent, and yourself, is this: Be prepared for what might come. Complete the paperwork, explore the options, discuss his wishes, create a plan. When using this book, after reading the sections that apply to your current situation, take a look at some issues that you are not yet dealing with—but may very well have to tackle one day.

Staying one day ahead, one question ahead, one chapter ahead will give you and your parent time to consider the options carefully. It will help ensure that your parent has choices and receives the best care possible. And just as important, planning ahead will mean far less work, less stress, and fewer headaches for you. It should even give you a little peace of mind.

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Ten Survival Tips

Whether you are already deep in the trenches of parentcare or just beginning your journey, here are a few key tips for surviving the job. All of them are discussed in detail later in the book, but they are useful to know from the get-go.

1. **ASSESS.** If you are racing frantically, stop. Sit with yourself for a moment, be still, breathe deeply, unclench your jaw, and clear your mind. Now, using the most rational (and least emotional) corner of your brain, ask yourself: What really must be done and what can be deleted from your crowded to-do list? Once you know that, determine what has to be done by you and what can be done by someone else. Prioritize, and once you take an item off the list, let go of it.

2. **ORGANIZE.** Locate important documents. Keep a record of key contacts (doctors, aides, lawyers, pharmacist, and so on), passwords, and your parent's medical history in a document that you can access from your phone or other devices.
**SIGNS THAT YOUR PARENT NEEDS HELP**

If you aren’t yet in the throes of caring for your parent, how do you know when to get involved? As this chapter makes clear, “sometime in the future” can become “today” quite suddenly, so don’t delay. Have the conversations outlined here, and be sure your parent’s legal and financial affairs are in order.

If that’s all been done and your parent is living on her own quite well, be aware of signs of trouble, particularly any changes in her behavior, appearance, or habits. If you suspect something is off, get involved right away. It could be a sign of illness or depression, or a signal that a problem is imminent, such as a fall, car accident, or nutritional deficiencies. Talk with your parent and/or her doctor. Some clues that your parent needs help:

- She’s unsteady. Is she wobbly on the stairs? Is her gait uneven? Does she get dizzy getting up from a chair? Or has she already fallen?
- His personal hygiene has fallen to the wayside. Is your parent skipping showers, forgetting to shave, looking unkempt?
- Your parent has gained or lost weight, which could be a sign of illness or depression, or an indication that she’s having difficulty shopping and cooking.
- The house and yard are no longer maintained. Is your mother’s beloved flower garden weedy, her usually clean house dusty, or the dishes piled up in the sink?
- Her personality has changed. Is your sweet mother suddenly critical or irritable? Your vocal father suddenly quiet and compliant?
- There’s nothing to eat. Is there food in the refrigerator? Is it spoiled and moldy?
- The mail is unopened or bills are unpaid.
- She misses appointments, gets lost, forgets important information, or loses things.
- The car has dents, your parent has a traffic violation, or you simply don’t feel safe letting your children in the car with Grandpa driving.
- Your parent no longer does things she used to enjoy. Has she stopped going to her bridge club, doing the crossword puzzle, or seeing her friends?
- The mail is suddenly full of new subscriptions, sweepstakes entries, and requests for donations. Or your parent has a new best friend. This could be a sign of fraud.


4. **TAKE CARE OF YOURSELF.** Be sure to get away from it all from time to time—physically, mentally, and emotionally. Make an effort to eat well, exercise, see friends, and rest. Caring for yourself will mean better care for your parent.
5. GET HELP. You do not have to—and should not try to—do it all. Get others involved, tap into community services, hire aides, and look into other housing options. Get help long before you think you’ll need it.

6. COMMUNICATE. Keep lines of communication open—with your parent, doctors, aides, and especially your siblings. Talk with them about who will do what and how you can support each other. Consider ways to compensate a sibling who is doing the bulk of the work.

7. SHOW RESPECT. Despite the toll of aging and illness, your parent is still an adult and still your parent. As difficult as it might be sometimes, treat her with respect. Hear her views.


9. PREPARE FOR THE END. Everyone will be focused on keeping your parent alive, which is natural, but this single-minded quest often makes people miserable. Question it. What does your parent want most (time, mobility, comfort, lucidity)? Be sure her goals are at the center of all decisions.

10. BE SPONTANEOUS. Do something with your parent that’s fun and unexpected, something that has nothing to do with doctors, medications, or aides. In all your time of caregiving, this will be one of the moments you’ll remember most fondly.

Critical Conversations

Although it can become too late quite suddenly, it is never too soon to talk to your parent and siblings about the future—her medical care, housing, finances, and personal needs. Obviously, if your mother is extremely sick and frail, these talks are urgent. But even if she is relatively healthy and independent, planning for the future is vital.

No one wants to deal with this. No one wants to imagine, much less discuss, a time when nursing homes or, God forbid, end-of-life decisions are necessary. It can be awkward and difficult to bring up, and also feel morbid or depressing, or as if you’re rushing your parent to a place no one wants to go.

And if you’re already in the thick of it, who has the time? Your mother needs help getting meals, she’s convinced the aide is a thief, and your siblings aren’t helping out. How are you supposed to make plans for the future when the here and now is so pressing?

Or maybe you think the planning’s been done. She has a will. She’s signed all the legal documents. She plans on staying in her house. And you know very well that she doesn’t want things “dragged out.”
If only it were that simple. What happens when your mom is in the hospital and your dad is left on his own? What happens when your mother needs someone to bathe her, dress her, and feed her? What happens when the doctor turns to you and says, “Should we put her on a respirator?” Are you ready? Really?

Go ahead. Have the conversations. Don’t put this off. Talk with your parent and, depending upon the situation, hold a family meeting to discuss your parent’s current care and future needs. Assign jobs, sort out finances, and make plans for what sort of care he will need as he grows more frail.

For your parent, planning ahead ensures that he has a say in his future, it affords him more choices, and it gives him time to prepare for change. If your father is encouraged to think about the possibility of moving out of his house long before such a move is an issue, it will be easier for him to make the move if it does, one day, become necessary.

For you, planning means less work when your parent needs help (because plans are in place), it means you aren’t always reacting to a crisis, and it means peace of mind.

Do it now because it is much, much easier to have these discussions when there is no dire problem at hand, when you are talking about some distant possibility, when it’s a matter of “What if . . .” Mom, what if one day you couldn’t handle your own finances?

Talk now; you’ll be glad you did.

**Your Reluctance**

Admittedly, asking your father about his finances or anticipating a time when he can no longer take care of himself is not easy. You might have a relationship in which personal issues, particularly his personal issues, are not discussed. Raising them might upset a relatively comfortable balance.

If your parent is a domineering or protective force in your life, you risk losing—at least for a moment—the role of the child. And you could find yourself taking on a strange, and not particularly welcome, new role.

More difficult than anything else, such conversations force you and your parent to acknowledge openly that he very likely will decline, will need help, and is indeed mortal.

Certain subjects—money, death—might make you particularly uneasy. But the truth is that your parent probably shares your concerns, and your reluctance. In fact, your mother might be keeping quiet because she is worried about upsetting you. Breaking the silence might be awkward, but once everyone’s gotten over the initial discomfort, it should be a welcome relief for all.

Keep in mind that talking about the worst-case scenarios won’t make them come true, and refusing to talk about them won’t make them go away. Ignoring the inevitable will only leave you unprepared for a crisis that will almost surely one day come.

**Breaking the Silence**

So how does one start such conversations? That will depend on the situation and your relationship.

If you are caring for a parent who is already quite frail or has a serious diagnosis, and questions are already hovering, you might just tackle this head-on. Mom, given your health and what the
医生告诉我们，我认为我们需要谈论一些事情。

如果事情不紧急，你更愿意采用一种不那么直接的方法，向父母询问建议是一个好的开场。父母喜欢提供建议。

爸爸，弗雷德和我正在存钱为我们的退休生活做准备，我只是想知道你是如何处理这个问题的。你认为多少是足够多的？你担心长期护理的费用吗？你觉得你存够了吗？

或者，你可以从询问父母的生活习惯开始——她最喜欢什么，她希望她能做得更好。然后，逐渐地将对话推进。她希望未来有什么？她担心什么？

你也可以从谈论别人的情况开始，比如一个朋友或家庭成员，他们已经年长。这个家庭是如何处理的？有什么不同？如果你的父母将来处于类似的情况，你会怎么做？

如果你的父母照顾过年长的父母，问他们如何处理某些问题，哪些是令人沮丧的，哪些是令人满意的。

或者，使用杂志文章或电视节目作为跳板。我在阅读一篇关于新进阶技术的文章。你听说过这些吗，妈妈？

如果面对面的讨论太困难，写下一些问题给你的父母。告诉她，这些是你关心的一些事情，你希望她考虑一下。然后计划一个时间坐下来讨论。

**聆听**

无论从哪里开始，开始时都要倾听，即使你有特定的问题想讨论或坚定的信念关于应该做什么。

你可能会确信你的父亲需要搬进辅助生活。

### WHEN YOU TALK

- 选择一个你和你的父母都平静且休息充足的时间，而且不要被打断。
- 小心不要因为你的父母的担忧而认为他们愚蠢，或者他们提出的快速“解决方案”。
- 保持事实的开放——糟糕的医疗预后，一个重大的财务障碍，一个不太理想的住房选择。要温和，但不要说谎或隐藏信息，否则这将伤害他。
- 结束每一次讨论之前，确保你和你的父母都不会感到疲倦或不知所措。
- 让对话保持开放。一次讨论只是打开了冰块，但这些话题需要重访。
- 如果你的父母改变话题或明确表示他们不想谈论某些东西，要温柔。告诉他们你关心他们，如果事情不紧急，那就放弃，再试一次。
facility, but for now, just ask questions. What does he worry about? What would ease his worries? How does he see this playing out? What does he still enjoy? What does he need from you?

And then listen. Really listen. Be open-minded to his views. You might assume that he’s worried about his daily care but discover that he is most frightened about becoming a burden, losing people’s respect, or being forgotten.

This is a whole new stage of life. Your parent is likely to have fears and hopes that he has never voiced before, ones that you haven’t considered.

For example, you may want to talk about finances, but your parent may be so afraid of falling or he may be so mired in grief that he can’t even think about money.

Once he’s had a chance to talk (without interruption), let him know that you hear him. Repeating what he’s said, using slightly different words, assures him that you get it. I understand that seeing your grandchildren is the most important thing for you now.

If you listen first, you will probably learn something, and your parent will be more likely to listen to your views, in turn.

What Not to Do
When you raise difficult subjects, avoid these common mistakes. Don’t:

MAKE DECISIONS FOR HIM. Often, with all the best intentions, siblings have discussions and make decisions and then present a master plan to a parent. Ben and I found an assisted living home near us. It’s perfect. We’ve talked to a real estate agent about getting your house on the market, and he says we can make this happen before November.

There are few more effective ways of blocking any further conversation.

ARRIVE ARMED WITH PAPERWORK. Pages of legal documents and brochures about retirement homes will only overwhelm your parent. This first conversation is just an opener, not a homework session.

TREAT YOUR PARENT LIKE A CHILD (OR IMBECILE). No matter how sick or confused your parent might be, he is an adult. Don’t talk down to him. Avoid the urge to nag or lecture.

TALK OVER TURKEY. Or birthday candles, or Christmas or Hanukkah presents. The holidays might be the only time you’re all together, but you probably won’t get a great response if you pull out a living will and pen while the pumpkin pie is making the rounds. If this is the only time you can talk, then give your parent a little notice and talk when the festivities are over.

What to Talk About
Here are a few major topics to get you started. All of these issues are discussed in detail in later chapters, including suggestions on how to talk about them. You won’t be able to cover all of this in one sitting, most certainly. Discuss what you can, and come back to other topics later.

NEEDS AND GOALS. What does your parent most want out of her life now? What matters to her? What does she enjoy? What does she still hope to do?

It might be something grand—take a trip, finish a project, see a monument—or it might be something simple.
AVOID MAKING PROMISES

Even though you might believe fervently that you will never ever put your parent in a nursing home, you simply don’t know what the future holds, either for your parent or for you. Your parent may become so ill that you cannot continue to manage her care. Your own life may change in such a way that you cannot give your parent the attention that you assumed you could.

Given such possibilities, don’t put yourself in the position of having to break a promise; don’t make it in the first place. If your parent asks you to promise that you will never put her in a nursing home, assure her that you will do whatever you can to avoid it and that you will never abandon her.

Perhaps your mom loves having lunch with a friend, talking with her grandchildren, watching the birds at the feeder, or listening to music. Or maybe your father wants to go trout fishing again, see a lake he loved as a child, or just tinker with some projects around his house.

Does he care more about staying in his home, being safe, or being near family? Does she want to continue to garden or play the piano wherever she lives?

All other conversations, about housing and finances and medical care, should be based on your parent’s particular goals and priorities.

DAILY ACTIVITIES. Before you plan the future, sort out the present. How is your parent managing day to day? You will witness some of this, but ask him what he considers to be the biggest obstacles.

Can he bathe and groom himself? Can he get to the grocery store and prepare meals? Does he fall now and then or feel unstable? Can he keep track of bills and write checks? Is he still driving?

There are solutions to most issues (discussed throughout the book), but you can’t help him if you don’t know what the problems are.

Your parent might be embarrassed about certain issues. Probe gently. Assure him that most problems are common and manageable and that admitting to them doesn’t mean you’ll cart him off to a “home.”

HOUSING. How does he feel about his current housing situation? Can changes be made to make life more manageable? What about the future? Where would he want to live if he could no longer live at home? What if it isn’t possible for him to live with other family members? If he has to move, what is most important to him (staying in his hometown, proximity to you, the ability to keep a pet with him, climate)?

Even if your family has no interest in any sort of senior housing, consider all the options. Visit a few facilities. Living at home can be lonely and, unless there are ample resources or generous community services, unfeasible.

FINANCIAL AND LEGAL ISSUES. What are your parent’s current financial needs and potential future needs? Can she meet these needs? Is she tapping into all the benefits and discounts for which she
is eligible? Is she spending with abandon or saving so fiercely that it’s dangerous? Is her insurance—including life, health, home, and auto insurance—adequate and current? Can she simplify her finances?

The biggest financial issue for most elderly people is the cost of long-term care. Medicare covers the majority of doctor bills, hospital bills, laboratory tests, and even a limited amount of nursing care, but it does not cover the kind of day-to-day care most elderly people eventually need—aides, companions, and homemakers, or extended care in a nursing home or other facility.

These bills can be astronomical. Such care can cost more than $80,000 a year, devouring what seemed like a comfortable nest egg. Those who have long-term illnesses or disabilities often have to pay out of pocket until they are broke, and then they go on Medicaid, the government’s insurance for the poor. Consider how your parent and family might handle such expenses.

Also, has your parent executed all necessary legal papers, including a will, durable power of attorney, and advance directives? Is there anything she might do to protect her estate from excessive taxes or, if she has little savings, to get on Medicaid early?

**MEDICAL CARE.** Does your parent have a good primary physician whom she trusts? Does this doctor communicate with her other physicians and coordinate all of her care? Does he or she take her complaints seriously and pay attention to issues that are not life threatening but troubling nonetheless? Some doctors give short shrift to mild memory loss, incontinence, depression, stiff joints, and anxiety, even though these issues will make your parent’s life (and yours) difficult.

If your parent couldn’t make medical decisions for herself at some point, whom does she trust to do that for her? Has she legally named a health care proxy to make these decisions for her? Has she talked to that person in depth about her wishes?

What are your parent’s goals concerning medical care? What should be considered when making medical decisions? What’s most important to her—time, mobility, comfort, lucidity? Any time medical decisions are made, talk with the doctor and your parent.

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**ON THE LOOKOUT FOR FRAUD**

The elderly are conned routinely. Don’t think for one minute that your parent is immune, no matter how smart, capable, or tough he might be.

Scams run the gamut from sweepstakes and lotteries, to reverse mortgages and investments, to aides, friends, and family members who tap into your parent’s heart and checkbook.

The best prevention is to alert your parent to common scams and to be sure he isn’t isolated because a lonely, worried, elderly person is the perfect target. See Chapter 16 for more on protecting your parent from being swindled and what to do when it happens.
about the goals of treatment, the likely outcomes, and other options for care.

**END-OF-LIFE CARE.** This is a tough subject to discuss, no doubt about it, but it is a crucial one. Don’t ignore it because such discussions could save your family from untold agony and grief.

Despite any promises made or papers signed, many people die in pain, afraid, and hooked to machines. They die after agonizing medical treatments of questionable value.

Talk—really talk—to your parent about her medical state and wishes concerning aggressive medical care. Get her to sign a living will and health care proxy, but realize that these documents are just a starting point. Alone, they will not protect your parent from unwanted treatments and a painful death.

Don’t accept vague (and not terribly helpful) comments like, “Don’t drag it out” or “When I’m at that point, pull the plug.” Push the conversation further.

What frightens your parent about dying? What level of pain, dependence, and disability would be unbearable? Is there a certain point after which she would no longer want life-sustaining medical care, such as a ventilator, artificial nutrition and hydration, or surgery? Would she prefer that treatments be focused instead on other goals, such as comfort, mobility, or lucidity? What does she think about hospice care?

Ask her doctor to describe various treatment options that might lie ahead, and the pros and cons of each. Help her get a realistic sense of what can be done and what can’t.

Also, talk with your parent and the doctor about getting an “at-home” Do Not Resuscitate order or POLST (Physician Orders for Life Sustaining

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**CRUCIAL DOCUMENTS**

Whatever else you do, be sure your parent has the following:

**AN UPDATED AND VALID WILL.** This ensures that his belongings (no matter how extensive or meager) will be allocated according to his wishes. A current will also reduces the likelihood of family conflict and complicated probate. And for a larger estate, a properly drafted will can reduce taxes.

**A DURABLE POWER OF ATTORNEY.** This authorizes someone to act on your parent’s behalf, from signing checks to making housing choices, should he become incapacitated. Without one, your family might have to go to court to have a legal guardian named.

**ADVANCE DIRECTIVES.** These include a living will and a durable power of attorney for health care (also known as a health care proxy). The first outlines your parent’s wishes concerning end-of-life medical care, and the second gives a trusted relative or friend the authority to make health care decisions for your parent when he cannot make them for himself.
Treatment). Despite what TV shows suggest, cardiopulmonary resuscitation, or CPR—attempts to restore some function to the heart and lungs—is a brutal procedure. A sick, older person is unlikely to survive it or ever leave the hospital.

Once you know your parent’s wishes, you may have to brace yourself to make some tough decisions and to fight a system that is focused on aggressive treatment.

For more on these documents and talking about end-of-life care, see pages 368 and 527.

Your Parent’s Denial
When your parent is hiding behind denial or simply dodging the issues—Oh, honey, why do you bring up such dreadful things? Everything is fine. Let’s talk about something more pleasant—grant her some of that protection. Be patient and try to understand her fears and the reasons why she might not want to face facts. Old age and the disability and dependence that often come with it are, obviously, difficult to accept. Denial and avoidance are natural responses.

“If your parent has a medical condition or diagnosis that emergency crews would need to know about, make this information easily available.

Put essential medical and contact information, along with any living will, health care proxy, and advance medical orders in a clear plastic bag. Label the bag and tape it to the door of the refrigerator or the back of your parent’s front door (where emergency crews will look for it).

In addition, get your parent a medical emergency bracelet that identifies him and provides critical medical information.

After my father died, I was very worried about my mom being able to handle her finances. My dad always took care of everything that had to do with money. I don’t think my mother had ever even balanced the checkbook.

I said to Mom over and over, ‘Let’s review your financial situation,’ and I offered repeatedly to take care of her bills for her. She’d say, ‘Brenda, don’t worry about it. I’m fine.’ And then she’d change the subject.

Then my brother came to visit, and within a day he had Mom pulling out folders and showing him bank statements. By the time he left, she had handed over almost all of her financial stuff to him.

I was stunned. I mean, I was glad to have it settled, but I was also a little annoyed. I’m an accountant. He’s a teacher. I guess she feels that money is men’s work.

I probably should have thought to get him involved right from the start.”

—Brenda S.
Remind her that you care and want to be helpful, and then ask her to please think about the matter. You have planted a seed. She will surely give the subject some thought.

Give her a couple of weeks and then bring it up again. Mom, I know this is difficult for you. But if we talk about these things, we can make sure that you get the kind of care you want.

If you still are not successful, ask another family member or close family friend to talk with her. For whatever reasons, she may be more receptive to someone else.

You might also suggest that your mother talk with a member of the clergy, a social worker, a lawyer, or a doctor about certain matters. If that doesn’t work, you might call these people and ask them to raise the subject with her. It’s often easier for people to talk to and accept the advice of someone outside the family circle, especially if that person is a trusted professional.

If, no matter what you do, your parent remains steadfastly silent, talk with your siblings and prepare without her.

### CHECKLIST: INFORMATION YOU WILL NEED

Documents, information, and items that you are likely to need:

- Names, addresses, and phone numbers of:
  - doctors, dentists, pharmacist, and other medical providers and suppliers
  - lawyers, financial advisers, accountants, and insurance agents
  - banks, investment firms, and other financial institutions
  - clergy members or religious organizations
  - your parent’s relatives, close friends, caregivers, and neighbors
- Medical history (illnesses, medications, treatments, allergies, immunizations)
- Certificates of birth, marriage, divorce/separation, and citizenship
- Military/veteran’s papers
- Driver’s license and/or passport
- Your parent’s will and any codicils (amendments) to the will
- Durable power of attorney
- Living will and power of attorney for health care
- Keys to his house, office, safe-deposit box, and post office box, as well as combination to any safe or lock
- Insurance policies (life, health, disability, homeowner’s, and auto)
- Social Security, Medicare, and Medicaid numbers and identification cards
- A list of employers, dates of employment, and terms of employment
- Any business contracts or rental agreements
- Deed to his house or rental agreement
Gathering Vital Documents

As your parent grows increasingly frail, your family will need certain financial statements, contact information, and medical records. Locating these things when your parent can no longer guide you can be exceedingly difficult. Gather them—at least the most critical ones—now.

If your parent is infirm and you have to look for these papers without his help, start in the obvious places—a safe-deposit box, desk and bureau drawers, office files, and papers stacked on tables and in corners. If you have trouble locating certain documents, call your parent’s lawyer, accountant, or anyone else who has had a hand in his financial or legal affairs. Look for leads such as bills, canceled checks, receipts, address books, and letters.

You might be able to track down some documents on the Internet.

- Deeds or titles to real estate, automobiles, boats, and other vehicles
- The location of any valuables (including anything hidden away)
- A list of all charge, debit, and banking cards
- Passwords, access codes, PINs
- Any automatic bill-paying or electronic transfer arrangements
- Appraisals of personal property
- Copies of federal and state tax returns from the past three to five years
- Receipts from property taxes and other large recent payments
- Burial and funeral instructions, if any

Your parent or you should make lists of the following (there is a “Financial Planner” on page 651 and at careforagingparents.com that will help you organize this material):

- Monthly bills (utilities, taxes, mortgage, insurance premiums)
- Your parent’s assets, including the value of:
  - savings, checking, money market, and retirement accounts
  - stocks, bonds, and other securities
  - real estate
  - automobiles, boats, and other valuables
  - business ownership and partnership agreements
  - profit-sharing and pension plans
  - trust agreements
  - outstanding loans
- All debts, including mortgages and other loans, credit card balances, outstanding bills, and other liabilities
The Centers for Disease Control and Prevention website has a state-by-state list of offices to contact for vital records (cdc.gov/nchs/w2w.htm), as does the federal government’s website (usa.gov). The Department of Veterans Affairs (va.gov) and the Social Security Administration (ssa.gov) also have useful information.

Insurance companies will often provide information about a policy even when the request comes from a family member of the insured. The Social Security office, former employers, and the local office of veterans’ affairs might also be willing to send you information about pensions and other benefits.

Banks are not very open in these situations unless you have proper authorization or are dealing with a local bank where the manager knows your family. By law, banks can give out account information only to the owner of the account or the owner’s legal proxy or guardian.

“During my mother’s illness, I accumulated so much stuff—brochures from nursing homes, documents from lawyers, forms from Medicare, pamphlets from social service agencies. Every time I got something, I just tossed it into this giant box in my bedroom. Then whenever something came up, like when I wanted to get meals delivered to her while I was away, I would think, ‘Oh yeah, I have something on that,’ but I could never find it.

A friend came over one day and dumped out my box and started sorting through it. She spent the entire day organizing the whole mess.

That was the best thing anyone did for me during those two years. Not only could I find things quickly, but it made me feel better. I’d been feeling so out of control, and that gave me a little edge. It made an enormous difference.”

—Terry B.

Exploring the Options

Don’t wait until there is a crisis or you are completely frazzled to learn about community services and housing options. It will be too hard to do such research then, the options will be limited on short notice, and honestly, you should use such services long before you think you need them (because you need them long before you think you need them).

Starting Points

Your parent’s doctor might know about some local services or should be able to direct you to someone who does. Friends who have been in a similar situation might also be helpful. Beyond that: THE AREA AGENCY ON AGING is the best place to start. These agencies go by
a medley of names—bureau on aging, council of senior services, commission on the elderly, and so on. You can find the one for your parent’s town through the Eldercare Locator (eldercare.gov or 800-677-1116).

The agency will have information about many of the services, programs, and housing options available in your parent’s community. Although you can get general leads from an agency’s website, it’s a good idea to call. A staff member should be able to answer specific questions about your parent’s care.

**LOCAL SENIOR CENTERS, COMMUNITY GROUPS, AND RELIGIOUS ORGANIZATIONS** often offer or can refer you to local services, programs, volunteers, courses, and organizations.

**A HOSPITAL’S DISCHARGE PLANNER** or social services department is responsible for making sure that patients have the services they need when they leave the hospital. These caseworkers should know a great deal about the options in your parent’s community. Some will offer guidance even if your parent is not in the hospital.

Be aware, however, that some hospitals have agreements with certain agencies and facilities, and thus the discharge planners might be biased.

**EMPLOYEE ASSISTANCE PLANS** at larger companies often provide information on eldercare. See what your workplace offers. Some can refer you to services in other areas, and others will put you in touch with a trained care manager who can guide you.

**THE STATE LONG-TERM-CARE OMBUDSMAN’S OFFICE,** which represents residents of nursing homes and their families, can give you information about local nursing homes and other types of housing for the elderly (ltcombudsman.org).

**MEDICARE’S WEBSITE** (medicare.gov) explains coverage and benefits and provides information about home care and housing options.

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**CAUTION ON THE WEB**

Although there are a number of good websites on the topic of aging (see the ones listed in Useful Organizations on page 608), there are an abundance of useless ones and quite a few unsavory ones. Use the Internet with caution.

Care of the elderly is big business. Drug companies, insurance companies, medical supply companies, and others who are simply trying to sell something set up sites that appear to be reputable and unbiased—but aren’t.

Several large sites that offer general caregiving help and free personal assistance get generous commissions for leading people to specific nursing and assisted living homes. Others tilt articles to appease advertisers. A good dose of skepticism should see you through.
**A GERIATRIC CARE MANAGER** can (for a price) assess your parent’s needs and hook her up with local services or take over your parent’s care almost entirely. You can find one through the National Association of Professional Geriatric Care Managers (caremanager.org).

**ORGANIZATIONS FOR A PARTICULAR DISEASE** often have local chapters that can direct you to services and programs near where you live. Some of these organizations are listed in the Resources section, starting on page 610. You can also get referrals to national organizations from the National Health Information Center (health.gov/nhic) or the National Rehabilitation Information Center (naric.com).

**211.** Many states have established human service information lines, which are contacted by dialing 211 (or visiting 211.org). Operators are trained to link people to social services and local programs.

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**Getting Organized**

If you diligently write lists on scraps of paper and then misplace them, or if you’re constantly remembering things that you shouldn’t have forgotten in the first place, know that life is only going to get crazier now.

When a parent needs care, the reminders, names and numbers, appointments, bits of information, and to-do lists start pouring into your life like confetti. Organization is the only way you will survive this.

If you didn’t start out organized, pull it together now. Really, an hour or two of work now will save you many hours and untold frustrations later. You’ll find your own system, but here are a few possibilities to consider:

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**HAVE A PLAN B**

If your parent depends upon one person for her care, have a contingency plan ready in case that person is suddenly unavailable. Be sure that someone can step in on short notice, or that your mother can go to a senior center, adult day care, someone else’s house, or into a local senior residence for a temporary stay.

You don’t want to be caught in dire straits when life takes an unexpected turn. And life with an elderly parent is apt to take unexpected turns.
Once you have a master list of all essential names and phone numbers, create a “group” in your contact list that you can access from your phone, tablet, or a computer, anywhere at any time. (If your inner Luddite has kept you from such technology, do it the old-fashioned way, on a piece of paper or in an address book that you keep with you.) Have the most critical phone numbers on speed dial.

Put your parent’s medical information, passwords, and other critical information on a flash drive (that you carry with you) or in a document that can be accessed from any computer. A variety of apps allow you to do this, including Dropbox, Evernote, and Apple’s Notes. Keep these files up to date!

Set up an online calendar with all of your parent’s appointments and schedule that others can access. There are many to choose among (Google Calendar, Yahoo Calendar, Apple’s iCal, or Scrybe, to name a few).

Keep a log of your parent’s medical care, either on the aforementioned calendar or in a separate document (see page 643). Include dates of treatments, when medications were started and stopped, instructions, and symptoms. Then you can tell a doctor when a symptom began or remind a nurse when a medication was started.

Keep all other relevant information—documents, brochures, medical papers, and so on—in one location. Buy some folders and a file box, or an accordion file.

Rather than scribbling errands on scraps of paper and leaving Post-its around the house, have a single to-do list that is accessible from your phone or computer.

Download a scanner app to your cell phone so that you can scan important documents on the spot.

Get your parent signed up for automatic deposits and automatic bill paying.

If family and friends want to know the latest news, create a group email list, start a Facebook group, or use a web service such as CarePages (carepages.com) or Caring Bridge (caringbridge.org).

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**SIGNS THAT YOU NEED HELP**

Don’t wait for warning signs. If you are a primary caregiver, you need help. Period. Get siblings and other relatives, friends, volunteers, and professionals involved from the start.

Some signs that you need help urgently:
You are angry, frustrated, short-tempered; not eating or eating constantly; not sleeping, unable to get out of bed; losing weight or gaining weight; sick, anxious, crying at odd moments; wishing you hadn’t had that extra drink last night; or lashing out at your kids, your parent, your spouse, or anyone within earshot.

Contact the Eldercare Locator (eldercare.gov or 800-677-1116) to learn about local support services. Then use them.
WEBSITES THAT HELP YOU GET ORGANIZED

If a number of people are involved in your parent’s care, sign on to a caregiver website. Although they are all a bit different—and evolving—the simplest ones let you organize contact lists and post news, photos, and messages. Most include a calendar where you can keep track of appointments and work shifts, and post tasks that need doing so others can volunteer to help. A few let you store medical and legal information, get updates from doctors (if they are inclined to use the site), and keep track of medications and symptoms.

These sites let everyone involved communicate about your parent’s health, schedule, and needs. Does anyone have a small shower seat? Can someone sit with Dad for a few hours on Friday night?

Most sites have a free trial period and then charge some sort of fee. This is not a bad thing, as it generally means that they do not have advertisers, do not have a bias, and do not sell your information.

Of course, these sites are only as good as the people who use them. If people are diligent, then it’s a great way to be sure others know what’s what when you leave for a few days or to be sure that an aide gave Dad his evening pills.

It’s a growing market, but here are a few sites to consider: Lotsa Helping Hands (lotsahelpinghands.com), Caring Bridge (caringbridge.org), CareZone (carezone.com), Saturing (saturing.com), and Tyze (tyze.com).

- Each time you call a home care agency, lawyer, or social worker, make a note about the call (on your incredibly organized calendar, perhaps), including the name of the person you spoke with and what you talked about, so you can refer to it later. (But I spoke to Anne Preston on March 18, and she confirmed that the home health aide would start tomorrow.)

- Whenever you make calls to agencies, doctors, and so on, have all the necessary information in front of you, with your questions written out. Otherwise, you may forget an important question and have to go through all the secretaries and recorded announcements again. When you get the information you’re after, write it down so you can relay it reliably to others. Get into the habit of asking for people’s direct lines or extensions, and keep note of them.

- Confirm, confirm, confirm. It’s better to confirm an appointment the week and/or day before than to find out that your father’s physical therapist has taken an unscheduled vacation and his assistant forgot to cancel his appointments.

- Make copies of important papers—receipts, insurance claims, nursing home applications—before handing them over or putting them in the mail.

- If the days slip away from you try writing a detailed schedule to help you organize your time and use it more efficiently. You might not adhere to it
precisely, but it will help structure your day so you are not constantly think-
ing, I’ve got to get to the grocery store. I can’t believe I forgot to call the Social
Security office. Wasn’t someone supposed to pick up Mom’s walker? The task—or
the breather you so desperately need—will already be assigned to a time slot.

When You Can’t Be There

If you live far away or are busy at work, you have to be extra organized. You
must plan ahead because you don’t have the luxury of responding immediately to
a crisis. What are you going to do when you’re at work, two hundred miles away,
and you get a call that your father has taken a turn for the worse and needs help?

At least a third of all family care-
givers care from afar. They live at least
an hour away and usually four or more
hours away. About half of caregivers
work either full-time or part-time.

Not being with an elderly parent day
in and day out can make life easier in
some ways, but it increases the burden
in others. The cost of travel, phone calls,
and hired help can be hefty of course,
but it’s the worrying and guilt that can
be unbearable. Is she all right? How will
I know if she isn’t? Should I book a flight?
Should I take time off from work?

Forget the guilt trip, but do make the
most of your visits. Now more than ever,
organization and preparation are the
keys to your success—and your survival.

Take another good look at what’s
been discussed so far in this chapter.
Here are a few additional tips for orga-
nizing from a distance:

- Have all important phone numbers —
doctor, lawyer, aides, and so on—with
you at all times.

- Be sure that your parent, her doctor,
and anyone involved in her care know
how to reach you.

- Check out local services and facilities
well in advance.

- Sign her up for any helpful services as
soon as you think they might be of use.

- Establish a local support network.
Make a list of friends, family, or neigh-
bors who live near your parent. Let
these people know of your concern.
They can alert you to signs of trouble
and help out in a crunch.

- Have the name and number of a local
handyman. (A pipe just burst in your
mother’s house. Who are you going to
call?)

- Leave a duplicate of your parent’s
house key (or code to a security
system) with a trusted neighbor or
friend, and/or hide one outside her
house in case there is an emergency
and someone needs to get in.
• Get your parent hooked up to the Internet so she can communicate with you and others. You can find laptops and tablets that are very simple. Also set her up with Skype or another video chat service. This way, you can see your parent as well as hear her, which will help you spot problems. You might connect while you cook or your family eats dinner so your parent can be a part of things. It’s no work for you, and it will make her feel less isolated.

• Organize your visits in advance so you can accomplish as much as possible. If you need to meet with a doctor or lawyer, set up the appointment at least a month in advance, as their schedules fill quickly.

• When you are with your parent, try to identify possible problems. Is her gait unsteady? Has her weight, hygiene, or temperament changed? Are her bills piling up? Is her food spoiled? Is she getting out and doing things? Is she asking you to repeat yourself and forgetting important information? Be alert to signs of depression, infection, dementia, waning eyesight or hearing, and other ailments.

• Even though your life is busy, try to spend some time simply being with your parent, chatting, watching a movie, shopping, or just sitting quietly. A trip that’s all business misses a critical element.

• Learn to distinguish real emergencies from unfounded complaints. It’s okay to say that you can’t come right now, that you were just there last week. Reassure her without feeling guilty. (Be aware that unending complaints and requests for reassurance may be an early sign of dementia; if this is a new habit, talk to her doctor.)

• If your parent lives alone and doesn’t get out much, see if a relative or friend will stop by occasionally. A local church, senior center, or religious organization might know of volunteers who can check on your parent. Or you can hire a companion. If your parent has in-home care or lives in a nursing home or other institution, it is still important that someone check in on her regularly.

• Buy your parent an emergency response system (see page 120) so she can get help immediately if she falls or is injured.

• Although the Internet is amazing, sometimes it’s handy to have a copy of the phone book or yellow pages from your parent’s hometown to look up a home care agency, say, or track down a particular doctor.

• When things get unwieldy (preferably before they get unwieldy), consider hiring a geriatric care manager, or find out if a local agency offers subsidized care management. A manager can assess your parent’s needs, organize local services, handle emergencies, and keep you up to date.

• Above all, take care of yourself. Recognize and accept the limits of what you can do, and give yourself credit for all you are doing. Don’t hesitate to ask for help or use community services. And get support from friends or a professional counselor to help you alleviate stress and guilt.
Although it might not make sense immediately, caring for yourself during this time is one of the most important things you can do, both for yourself and for your parent.

Don’t flip past this chapter, thinking that you simply don’t have time for such things. My mother needs me. I can’t worry about myself right now. I’ll be fine.

Your parent’s care can consume an ever-expanding piece of your life and suck you into a swamp of anxiety, guilt, and resentment. Before you know it, you are too busy for friends, snapping at your spouse, distracted at work, hugging a bottle of wine, and constantly trying to shake a cold.

Handling six things and worrying about another four while, on some visceral level, feeling angry at the world isn’t healthy. It leads to irritability, isolation, depression, and, more often than one would imagine, physical illness.
You cannot take good care of your parent if you do not take care of yourself. It’s that simple. As any flight attendant will tell you, you have to put your oxygen mask on before you assist the person seated next to you.

So no matter what the demands on your time right now, take a step back. Breathe deeply and slowly. Get some perspective. And tend to yourself. Oddly enough, it will help you be a calmer, gentler, and more efficient caregiver.

**Setting Limits**

If there were such a thing as Caregivers Anonymous, the first step in the program would be to get rid of that little voice inside you that says, *I can do it all. I am responsible for everything. Whatever I do, it’s never enough.*

Of course you want to make your parent well, make her happy, make her safe. In fact, if it were possible for you to be with her every minute of the day, perhaps you would be. This is your parent, after all. She needs you.

But the truth is, you can’t be with her 24/7, and trying to do so will only exhaust and frustrate you without really helping her.

So how do you use your energies most effectively? If your mother has a sudden and severe illness, of course you’ll want to be there. But when her needs are more chronic, when you find yourself taking on more and more responsibility, you have to step back, take a realistic look at the situation, and establish some boundaries for yourself.

This might require a seismic shift in thinking, a great realization that you are not responsible for everything, that you cannot fix everything, that you need help, and that you have a life (or some semblance of a life) of your own.

As hard as this is, you might be surprised to discover that setting some limits relieves your guilt, eases the tension, and gives you more patience and energy for those things that only you can give.

> Like the waves of the ocean, it sometimes overwhelms me. I think I’m this incredibly strong person, but I’ve been spending all my time taking care of stuff for my parents and I’m the one who’s falling apart. It’s way too much. They are doing much better than I am.”

—Lou Ann W.
EXAMINE YOUR MOTIVATION. Why are you helping your parent? It sounds like an odd question, but it’s a healthy one to mull over. Do you feel that you have a cultural or religious duty to care for her? Do you view your parent’s care as an unfair burden that was dumped on you? Or are you helping because, given your parent’s situation and your priorities in life, this is what you gladly choose to do?

Your motivation might be complicated, but take a moment to think about it. Then consider your options, and make a conscious choice about your involvement in your parent’s care. If you can accept this as your choice, something you decided to do—not as

“...

your involvement in your parent’s care. If you can accept this as your choice, something you decided to do—not as

ACKNOWLEDGING THE JOB

Quite often, people tending to an elderly parent don’t identify themselves as caregivers. They think they are just doing what needs to be done, what anyone would do. She’s my mother, for Pete’s sake. She took care of me; I can take care of her. This is what families do. Convinced that this is somehow normal, they don’t understand why the task is so hard or why they are falling apart.

Although it’s true that people have cared for their parents throughout history, across cultures, and around the globe, much has changed. In fact, the sort of eldercare we face today is a relatively new phenomenon.

Just a couple of generations ago, people grew old, became ill, needed some care, and died. Today, people live for years and years with complex medical issues. They don’t simply need a loving touch and some hot food; they need catheters, oxygen, and eight different medications.

They need someone to put a spoon in their mouths, get them on the toilet, pull on their socks, and remind them what day and month it is.

The caregiver side of this coin has changed as well. Families often live far apart, and women, the traditional caregivers, are working and having children later.

For all these reasons, the job has become far more demanding, complex, and prolonged. It is not just what families do. Caregivers jeopardize their health, careers, finances, and relationships. They have a higher rate of depression, insomnia, illness, and even mortality. This task is literally killing them.

Caregiving is hard work. The first step in taking care of yourself, and thus taking better care of your parent, is to acknowledge that this is a big job, and that you cannot do it yourself. You need lots of help and support.
something your parent, your siblings, or a judgmental or unjust world has dumped on you—the work you do for your parent will still be difficult, but it will feel more like an interruption and less like an imposition. It will be a conscious decision that is more about love and family and less about old debts and unmet needs.

IDENTIFY THE NEED. You might know what needs to be done, but be specific. Write it down.

What does your parent need, and what is a luxury or perceived need? Does she need someone at her house every afternoon? Does she need help with bathing and dressing? Help with medications? Rides to the doctor? Make a checklist of her essential needs—the musts—and then a second list of what would be nice—the extras. Star anything on the list that only you can do (and be very selective here).

Writing it all down, preferably with her input, will help you see what is crucial, what can be skipped, and what can be done by others.

Now what about you? What are the “musts” in your life? What has to be done? What can be pushed off your to-do list? And what do you need in your life so you can stay sane? A night out each week with a friend? An hour each morning for exercise? Time with your kids?

CREATE A PLAN. Now that you have your lists, determine what you can reasonably do and, more important, what you have to stop trying to do.

Day to day, your parent’s care may seem more pressing than other matters in your life—everything you do for your parent at this point might seem essential—but think about it. Visiting your mother every day may be ideal, but would she be okay with fewer visits? As you decide what’s truly necessary, consider what you may be ignoring or giving up because of your parent’s care. Are you willing to jeopardize your own health? Neglect your children? Damage your career?

You might decide you will handle her finances, confer with her doctors, and visit twice a week, but not more than that. Or, if you live with your parent, you might create some parameters, some specific times of day when you can help her and other times when your family has some privacy.

Be conservative in your plan; it’s always easier to increase your commitment than to decrease it. Don’t promise to make three regular visits if that puts you over the edge; keep it at two.

GET COMPENSATED

If you are logging a lot of caregiver hours and your siblings simply can’t (or won’t) help much, then consider getting some compensation for all you are doing, especially if you have scaled back hours at your real job. Seriously. Don’t be a martyr. A long-term caregiving job can wreak financial havoc in your life and create a lot of resentment. Some sort of compensation can ease the strain and mollify family relations. See page 66 on how to create a caregiver contract and calculate compensation.
Dole out any jobs you can. You do not need to take this all on by yourself, nor should you try to. Get other family members involved, use community services, hire help, and when necessary, consider other housing options.

Siblings, in particular, should be called on right away. They might have different ideas about your father’s care or different ways of doing things, but they should be involved. If you begin this as a family effort when the tasks are smaller, you will have each other further down the road when the needs and responsibilities tend to be more monumental. (See page 61 for more on dealing with siblings.)

Let other people give you a hand as well. Someone might pick up your dog at the veterinarian, bring over a casserole, water your plants, or stay with your parent for an afternoon.

However you do it, get help!

Let go of futile efforts. Don’t waste precious energy trying to get your parent to change her ways if it’s clear that she won’t. Talk with your parent about your concerns, get others to help in the effort, and show her other options. If she still won’t budge, and she is mentally competent, you might have to give up.

For example, if you are spending a lot of time researching group homes for the elderly, and your mother has absolutely no intention of moving, at some point you need to stop the hunt and get on with more productive tasks, such as safeguarding her house and finding community and in-home services.

You might feel that you have failed, but you haven’t. Your mother might be in a somewhat risky situation. She might fall or run out of money. But you have done what you can, and you cannot do
任何。你不能责怪自己，如果你的父母的决定，在你的想法中，是不好的。

同样，如果你的兄弟姐妹只是简单地不帮忙，推搡和干扰，但到某个点你学会接受它。请再推一推。有一家人开过会。但最终，让它去。不要浪费宝贵的时间。

转变成无望的事业是一个巨大的成就。然后，你可以接受生活，工作在现有的范围内。

学会说不。看护者往往是不好说不的，他们给出的建议是说不的。女性尤其如此，但这既没有帮助也不好。

说服自己，说不的某些事情，不仅是可以，而且是必要的。练习。试着对狗说。

Say no to the mirror. Just get the word out.

Confronted with a parent’s escalating needs, you may learn, perhaps for the first time in your life, how to act on your own behalf.

When I retired, I didn’t tell my mother. I didn’t want her to think I was more available, that I had more time for her. I had been taking care of her for several years, and when I retired, I realized there was a lot that I wanted to do for myself, a lot that I had neglected because of her.

I told her that I was working from home more, in case she called and found me there, but I didn’t tell her that I had retired. And I have never regretted it.”

—Barbara F.
**STICK TO YOUR GUNS.** Sure, you can decide to cut back on some visits, even put a plan in writing, but how do you stick to it?

Say you decide that your marriage needs more attention, but just as you and your spouse settle in for a quiet evening together, the first in weeks, you find yourself feeling guilty for not being with Dad. You’re short with your husband and end up calling your father in the midst of dinner, just to check in.

Be firm in your resolve. If you decide that you are not going to concern yourself with your father’s financial affairs anymore because you have handed that job over to another family member, don’t spend an evening researching reverse mortgages. If you’ve told your mother you cannot be interrupted during work, and she continues to call hourly, remind her gently that this is not the time to talk and that you’ll call her when you get home. Then hang up. (Be aware, however, that a constant need for reassurance may be an early sign of dementia.)

**NO COMPARISONS.** Whatever you decide to do, and not to do, don’t be influenced by what someone else is doing. Just because a friend visits her father every afternoon doesn’t mean that you should change your schedule. Just because a guy in your support group cared for his mother in his own home for 12 years, don’t feel that you aren’t doing enough. Every situation is different. Every relationship is different. Each person faces different demands and has different supports. Only you can create the right balance for yourself. Find it and accept it.

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**Emotional Minefields**

Simply surviving parentcare requires that you deal with some potent emotions. Believe it or not, the reactions you are experiencing now, even the ones that seem disturbingly illogical, cruel, childish, or out of character, are completely normal and common. Most of them can be tempered.

“I used to spend hours trying to convince my parents to move out of their big house and to organize their finances. But they didn’t do anything. They would ask me questions and listen and act like they were going to do something about it. But they never did.

And then I realized, they are not going to change. They are not going to move until something forces them to. And there is nothing I can do about it. It was terribly difficult to back off. You want so much to help, and you know things are only going to get worse. It took me three years to give up and let go, and I still struggle with it sometimes. I just have to go along and see what happens next.”

—Diane P.
When I was taking care of my dad, I was so exhausted and I lost a lot of weight. I went down to 103 and looked gaunt. When you feel like throwing up all the time, you don’t eat.”

—Maggie B.

Guilt
Ah, guilt, the constant companion of caregivers. Women are particularly good at guilt. I’m not doing enough, I’m not doing it right, I should have done something else. And isn’t it interesting that we can feel so guilty for not doing enough, and in the very same breath be resentful that we have to do so much?

Guilt is not a particularly useful emotion, especially in this case. So get rid of it. Summon it up, vomit it out into a trash bag, tie it up, and toss it out. And then do it again and again, because guilt has a sneaky habit of reappearing.

Stop focusing on what you are not doing, or what you imagine you should be doing, and focus instead on what you are doing for your parent (and for others in your life). Make a list of these things and be sure to include everything that you provide—emotional support, phone calls, visits, talks with doctors, help with financial matters, and so on. What would your parent’s life be like without you?

Recognize and be proud of what you are giving, and give it generously. But please, dump the guilt.

Helplessness and Worry
Given all the medical issues, the costs, the paperwork, and the various players and services involved, it’s no wonder caregivers often feel stymied and helpless.

The fact is, a lot is out of our control. No matter what we do, our parents become frailer. Death looms.

It’s a downward trajectory that sometimes feels like a free fall. The sense of powerlessness and the worry that goes with it can be paralyzing.

TAKE ACTION. Don’t stew—do.

Don’t just complain to your friends about a chronically late home care worker, a rude orderly, or a poorly run meal service. Talk to the person involved, and if he’s not responsive, speak to a supervisor. Be pleasant but persistent. Take action.

Ask questions when dealing with professionals. Be an educated advocate for yourself and your parent, and don’t be afraid to speak up when necessary.

Getting answers and taking action is far better than letting problems fester. It will give you some sense of control. Most important, it often leads to solutions.

SET ASIDE A WORRY TIME. Rather than stewing during a meeting at work or lying awake at three in the morning, set aside a specific time, 15 minutes or half an hour each day, maybe during a walk or a commute to work just for worrying. It sounds ridiculous, but it works.

When you can’t stop fretting, jot down whatever it is you are thinking about and know that you will contemplate it during your “worry time.” Then, go back to sleep! It’s been scheduled. In the light of day, you’ll probably discover that it wasn’t all that critical after all.

Resentment and Anger
Your parent’s care is consuming your life. Your siblings aren’t helping. Your spouse
isn’t supportive. The world isn’t fair. And now, your heart is racing and your head aches. Resentment can be toxic.

It can also be self-perpetuating. You resent your parent for being a burden, then feel guilty for resenting him, then resent him because he’s making you feel bad about yourself.

Anger is more difficult to deal with because it is so hot and blinding. Be careful. Anger can lead to rash acts, regrettable words, broken relationships, and abuse.

**WALK AWAY.** When you are angry, don’t take any action. Get away from the situation and simmer down. Breathe deeply.

**GET HELP.** Right away. Contact the area agency on aging (eldercare.gov) and learn about adult day services, respite care, in-home care, and other local services. Then use them.

**GET SUPPORT.** A support group is great for defusing anger and resentment. These emotions are common; sometimes simply realizing that you’re not alone can help. Or talk with a therapist individually.

**ASK WHY.** Once you’re calm, address the reason for your feelings. You don’t want to explode, but you also don’t want to implode. What makes you so stomping mad? Is it really your parent’s care, or is it your brother’s criticism, your fears about your own old age, or a sense that somebody, somewhere, should be thanking you? What is causing this reaction?

**REFRAME IT.** That is, rather than simply being angry or wishing that a person or situation were different, think about what you can do to change the situation.

If you resent your parent because you are doing too much and missing out on...
adapting to new roles

What’s difficult for me is the guilt that I’m not doing enough. After all the logistics of working stuff out and doing payroll every weekend, I end up not seeing my mother as much as I would like. It feels like I’m being pulled in a million directions. I don’t see my friends, I don’t see my grandchildren as much, and my children don’t want to hear my ‘laundry list’ of reasons why I’m not available for them.”

—Diana R.

your own life, then back off. Do less. If your siblings aren’t helping, talk to them about how they might help and/or arrange to be compensated for your work (see page 66). If you simply need a thank-you and some validation, let them know.

If you resent your spouse for not sympathizing or helping out more, talk with him (or her) about specific ways in which he can help and exactly what it is you need from him. (You might also need to lower your expectations.)

Don’t expect others to simply know that they should help out or thank you or do something different. Let them know (calmly, of course).

BEWARE THE PITY PIT. Don’t be a martyr. It seems unthinkable, but it’s easy to fall into a pit of self-pity and become so comfortable in that pit that you start to wallow in it. From this vantage point, the world is cleanly divided into black and white. I’m good; they are bad.

Of course, this will only hurt you in the long run.

WRITE. If you have trouble thinking clearly about this, write about it. Don’t worry about grammar or style, just vent all over the page. Writing can help blow off a little steam without burning anyone in the process. It can also, with time, clarify some issues and, as a result, lead to solutions.

FORGIVE YOURSELF. If you snap at your parent, argue with your spouse, or devour a box of doughnuts, let it go. You’ve got a lot on your plate (besides doughnuts). It’s natural and normal. Move on.

Disgust
This emotion might not be discussed openly, but most caregivers know about it, and it is no small matter.

Obviously, changing a diaper or cleaning up an “accident” will rattle anyone’s nerves. Incontinence is one of the

WHEN YOU’RE AT THE EDGE

The stress of caregiving can drive people to do things they never imagined possible. If you find yourself lashing out at your parent, neglecting him, threatening him, yelling at him, striking him (even lightly), or exploiting him financially or otherwise, get away from him immediately. Call a friend or neighbor to take over. You need help, and you need it now. Contact the area agency on aging (eldercare.gov or 800-677-1116) for support and respite services.
biggest reasons people get outside help or move a parent.

But more mundane things—a parent’s eating habits, bodily noises, or odors—can also repulse. Even if you love your parent dearly, the scents and sounds that come with aging can bring on powerful waves of disgust. Your reactions will be compounded by your stress and exhaustion. Your reserve tank is on empty.

The fact is, some of this you simply have to get over. Your mother can’t change the fact that she has difficulty chewing, and making her feel bad about it will only, well, make her feel bad about it. Try to understand that this is a by-product of age, illness, and medications.

Some things can be improved with cologne (for her, not you), air freshener, mouthwash, and a box of tissues. Also, check out any relevant sections in this book for ways to improve the situation.

Your best defense is a good sense of humor. Talking with others (friends, a support group, an online chat room) might also strengthen your resolve and, at least for a moment, help you laugh about it.

When you simply can’t take it, get help. Maybe someone can come in the morning and help her with toileting and hygiene. Or maybe she can go to adult day care several days a week.

Get help, because although some discomfort is normal, disgust can lead to poor care and harsh words.

**Grief**

Parentcare is, at its core, about loss and grief. But it’s not the normal sort of grief. It is a perverse grief, a good-bye that can’t yet be said, although it hangs darkly overhead.

When a parent grows frail or forgetful, the losses come in small, unexpected doses—a fall, a missed name, a fender bender, a shaky hand, another nap. The loss drags on, always with us, weighing on us, and yet difficult to define or resolve.

And so, tears come in strange spurts. Grief explodes in anger and confusion. It’s not clear what it is, this chronic, simmering grief, and it can be agonizing and unbearably lonely.

Whatever else is happening, whatever sort of relationship you have with your parent, try to acknowledge your grief. You might be grieving the impending loss of a parent you adore or grieving a relationship you never had. You might be mourning the loss of your childhood or feeling sad about your own aging process.

It’s a complex mix, but whatever the cause of grief, it’s important to recognize and allow it.

All of us grieve in our own way, at our own pace. The sadness can be constant,
or it may crash over you in waves at odd times. Or it might show itself in other ways—anger, bitterness, and depression.

Allow yourself time to grieve. Have a good cry. Spend time alone, or share your thoughts with others.

If you love your parent and will miss her, don’t allow this opportunity to let her know go by.

### 12 More Steps to a Healthy Mind-Set

Here are some additional ways to take care of yourself:

1. **TAKE FIVE**
   If you are caring for your parent on a regular basis, especially if you are living with her, remove yourself completely from the situation once in a while. You need to refuel, and you can’t do it without some distance. Get some respite before you are too distraught to plan or enjoy such a break.

---

**BE ALERT TO DEPRESSION**

Take care of yourself, get some exercise, see friends, set realistic goals, and make time for things you enjoy—ideally, *before* you’re in trouble. Be alert to signs of depression:

- feelings of sadness, hopelessness, worthlessness, or anxiety
- fatigue, exhaustion
- changes in eating or sleeping habits
- loss of interest in activities you once enjoyed
- social isolation (not calling or seeing people who used to be in your life)
- difficulty concentrating
- irritability
- bouts of tears
- vague physical symptoms (stomachaches, headaches, general pain)
- thoughts of death

Depression can be treated effectively with counseling and/or medication. Call your doctor, or for immediate help, call the local crisis intervention, suicide, or depression hotline, or 911.

For information about depression, online support, or a referral to a local specialist, contact the International Foundation for Research and Education on Depression (ifred.org) or Mental Health America (mentalhealthamerica.net or 800-969-6642).
You might take a vacation or you might simply take an afternoon off to sit in the park, see a friend, or have a pedicure. Set aside time in your regular schedule a few times a week to do as you please. If necessary, make arrangements for fill-in help or get your parent into a respite program.

Then, while you are away, be completely away. Think about something else. Talk about anything else. Clear your head.

2. A FRIEND, INDEED
When you are caring for an aging parent, quite often the first thing that goes is your social life. Invitations are turned down and friendships are put on hold because you simply do not have the time or the energy for them. If you are living with your parent, social isolation can become a serious problem.

Friends are more important now than ever. They can provide a sympathetic ear, make you laugh, get you thinking about other things, and remind you that you are not alone.

Studies show that caregivers who have social supports experience less depression and illness and are less overwhelmed by their responsibilities than those who don’t.

Rather than cutting yourself off, reach out to your friends. Find a way. Make it a priority. Go out for lunch, go for a walk, or make a phone date. Just as you would be there for them, your friends want to be there for you.

3. GET SUPPORT
You might think that you are not the type to join a support group, that you wouldn’t want to share with strangers, but try it. You can get practical tips, but mostly you’ll see that others face the same difficult issues and turbulent feelings, and this in itself can be an enormous relief.

Support groups—whether in person or online—offer a safe arena in which to air intimate problems, vent anger, or talk about painful emotions. Because you face similar situations, you can understand each other in a way that others, even best friends, cannot.

Support groups vary widely in terms of purpose and membership, and you may need to try two or three before finding one that meets your needs. Some groups are designed for anyone caring for a sick parent, whereas others zero in on specific issues—family relationships, Alzheimer’s, cancer, grief, or advocacy. Some are set up so people can share practical information and resources, and others function purely as emotional outlets. Some have leaders, others are unstructured. Although support groups are usually for the caregiver, some encourage parents to attend as well.

More and more venues for support and sharing are offered online,

“Sometimes in the evening I reach a point when I think, ‘I’d just rather not go out tonight.’ But I always come home from the support group feeling better. Because everyone in the group is dealing with someone with dementia, it helps me see that what my mom is doing is perfectly normal for this disease. I also see that what I’m feeling isn’t cruel or selfish or crazy. Even if I never see these people again when this is over, I’ll never forget them.”

—Barbara F.
The last time I went to my support group, a woman was talking about her father, who has dementia. She was taking care of him 24 hours a day, and she was so warm and had such a nice sense of humor about it all that I thought, ‘This woman is a saint.’ It made me feel terrible. Eventually I had to come to grips with it. That is her life; this is mine. I do the best I can.”

—Linda K.

which isn’t as intimate but is a whole lot easier—available when you want it and completely anonymous. However, be aware of advice given online; keep in mind the source.

To find local a support group, contact your area agency on aging (eldercare.gov or 800-677-1116). Caregiver Action Network (caregiveraction.com) has an online forum.

Most nursing homes, adult day-care centers, senior centers, and mental health clinics should also be able to refer you to nearby groups. If you are interested in a specific topic, contact the appropriate association, many of which either run support groups themselves or can refer you to one (for example, the Alzheimer’s Association, the American Cancer Society, or Alcoholics Anonymous).

4. AVOID THE COULDA-SHOULDA-WOULDA’S
Also known as the If-Only or the More-Better-Different Syndrome, this is a dangerous mind-set. I could have been better about that . . . I should do more . . . If only life were different . . .

Wishing for things that can’t be, regretting what is, or daydreaming about

MAINTAINING A SOCIAL LIFE

If you and your parent live together, or simply spend a lot of time together, you can still have a social life. You just have to be a little more creative, flexible, and determined.

If your parent wants to be included in a social event (and you want her to be included), have the guests come to your house rather than going out. Home is a more familiar and comfortable setting for your parent. It also means she can leave the room when she needs to rest, without breaking up the party.

Of course you might not want the extra work of cooking for a crowd, and there’s no reason for you to try to be Martha Stewart. Have a potluck supper or just order a pizza. People want to be together; what’s served is really secondary. (Friends can help cook and clean up, too.)

If your parent would rather not go out, or if you would rather not include her, don’t stay home just because it’s easier. Go out. Get a sibling or companion to stay with her. Even though it may seem like an extravagance, make yourself do it. It’s a worthwhile investment in your well-being.

See page 486 for tips on socializing when your parent has dementia.
what might have been is futile and potentially destructive if it keeps you from more productive tasks. It’s human nature to think this way, but try to focus on what is and what can be.

5. **SHIFT GEARS**
Whenever you are feeling Type A, think Type B. Researchers have actually timed people who run through red lights and blast their horns at pedestrians, and have found that these racers don’t save themselves any time at all. In fact, hurrying often slows things down because in the rush you are apt to spill food or misplace your car keys.

   It seems contradictory, but sometimes when life is hectic, it helps to slow down. Stay calm. Breathe. Unhunch your shoulders.

   If you are driving somewhere, and it takes 20 minutes to get there, don’t try to make it in 19. Leave extra time and then relax. Use that time to listen to your favorite music or book. Or simply relish the silence. Stay in the slow lane, wait until the light turns green, and leave the honking to the geese.

6. **EATING WELL**
When a parent needs care, any thought of a decent diet vanishes. Stressed and overwrought, people either fail to eat or find that a bag of Doritos is a just reward for a taxing day.

   And of course, racing from a doctor’s appointment to a work meeting to the bank leaves little time for fresh food. It’s 6:30 and people are hungry. What’s fast?

   Take-out food, chocolate fudge brownies, and an endless stream of caffeine might seem, in the moment, like the only option (and you do deserve a reward), but rethink this approach.

   Eating well will make a huge difference to your health, energy, and spirits. Furthermore, taking even half an hour to sit down with your family and have a real meal, rather than everyone eating out of a box on the fly, will have a surprising effect on everyone’s day and relationships.

7. **A LITTLE SWEAT**
There is nothing like a workout to shed pent-up emotions, clear a muddled head, and revive a tired body. Exercise protects people from the harmful effects of stress, elevates mood, lowers anxiety, and promotes self-esteem.

   **MAKE IT DOABLE.** Weight training and rigorous workouts are great, but if you hate that sort of thing, find something else. It’s better to walk one mile five
times a week and stick to it than to run three miles daily and give up after a week. An exercise regimen should last at least 20 minutes and be varied.

**MAKE IT SOCIAL.** Find an exercise partner. You will be less apt to excuse yourself from the routine, and you get to socialize while you sweat.

**MAKE IT USEFUL.** If you simply don’t have time for the gym, rake the yard, sweep the floor, or walk to work. Read the newspaper on a stationary bike or talk to a coworker while you walk.

**MAKE IT FUN.** Exercise doesn’t have to be boring. Play tennis, swim, skate, or dance.

**MAKE IT CHALLENGING.** Every now and then, push yourself. Challenging yourself physically seems to have a beneficial effect on stress and resiliency.

8. **ZZZZZS**
In studies of laboratory rats, scientists have found that severe sleep deprivation is always fatal. It is more harmful than starvation. For humans, life without sleep certainly feels deadly, causing irritability, poor concentration, lack of coordination, and forgetfulness. Make sleep a priority.

---

"During my father’s illness I got very depressed and closed in. I realized that I needed some outlet, a way of dealing with the constant anxiety. So I started drawing.

I hadn’t done any sketches for years, but I bought a pad and pencils and dug in. I find I can express my rage and fear in drawings better than I can with words. I sketch each night. It’s my sanity. I’ve actually gotten pretty good at it.”

—Eleanor R.

---

If you are having trouble sleeping, see the tips about dealing with insomnia on page 216.

9. **PURSUE YOUR HOBBY**
Hobbies, sports, crafts, and other such pursuits are not frivolous pastimes. They help clear your mind of your worries—perhaps just for a brief interlude—which allows you to regain some balance and energy.

If your parent’s care is a prolonged commitment, don’t forgo your pottery, gardening, painting, tennis, knitting, or javelin throwing—whatever it is that calms you.

Make it a point to find time for it. Take pleasure in it.

10. **SPIRITUAL SUPPORT**
Whether you are religious or not, spiritual issues often arise when a parent is sick. *How do I ease my anguish or grief? How do I face my own mortality? Why would a loving God do this?*

A little prayer can strengthen your will and focus your life. Nearly 75 percent of
caring for the caregiver

57
caregivers say they use prayer as a way of coping.

If going to religious services doesn’t interest you, or if you simply want a more personal discussion, most clergy are happy to meet with people individually. Just call. (You can send a donation if you want to repay the favor.)

Devotee or atheist, sometimes it helps to simply sit quietly in a peaceful place, listen to your soul, and remember your priorities.

II. RELAX
You don’t know how much stress you are carrying around until you sit in a relaxation or meditation class and let go of it. The techniques you learn there can be used anywhere, anytime, to ease the pressure. Classes in tai chi, meditation, and yoga, as well as in general relaxation, all relieve stress.

In fact, you can permanently change your response to stress and become a calmer, more relaxed person. So this is an opportunity not only for immediate relief, but also for personal growth.

I2. LOVE TO LAUGH
Laughter is a forgotten healer. It makes the world sane (or at least it makes the insanity more fun), and the body healthier. A good dose of humor bolsters the spirit, and hysterical laughter strengthens the immune system, improves circulation, and relieves stress.

Of course, howling with laughter when someone you love is ill or dying can feel like a sacrilege. You might think that you have to be solemn to reflect the seriousness of the situation and to show respect for your parent. But you don’t. You really don’t. It’s okay to laugh, no matter how sick or incompetent your parent may be.

Find something funny about the situation. (Dentures are funny, especially

My mother had a mastectomy, and sometimes forgets to put her prosthesis in. She’ll come downstairs with her shirt all askew and sagging, and after standing there for a minute or two, she’ll say, ‘Something is not right.’

I look at her and have to laugh. ‘Mom,’ I say, ‘you forgot your boob.’ And we’ll both giggle. She thinks it’s funny, too. It could happen to anyone. If we didn’t laugh, we would cry. It’s that sort of thing.”

—Greg C.
when your parent isn’t wearing them. Certain sourpuss nurses are funny. The Jell-O served in hospitals is funny. Sagging, loose skin under the arm is mildly amusing when it’s not your own.) See a slapstick movie, visit a goofy friend, scan the comics, play a joke on someone, clown around with your siblings.

Whenever you feel that you just can’t take it anymore (and ideally long before that point), find some way to laugh—a long, side-splitting, teary, wet-your-pants kind of laugh. It’s good medicine.

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The Male Caregiver

Eldercare has traditionally been the province of women—leaving them to care not only for their own parents, but their husbands’ parents as well—and they are still bearing the brunt of this job. However, men are becoming increasingly involved. Studies suggest that between 30 and 40 percent of caregivers are men (up from about 20 percent in 1996).

Although generalizations fail in so many ways (if you’ve seen one caregiver, you’ve seen one caregiver), there are some differences in how men and women typically approach this task. Both have strengths and weaknesses; the sexes might just learn a thing or two from each other.

Men are more apt to help with “hands-off” care, such as finances, legal matters, transportation, home maintenance, and hiring. Women, on the other hand, are more apt to handle the “hands-on” care, like dressing, bathing, feeding, toileting, and just plain being present.

Because most men grew up in an environment where women played the role of primary caregiver, they tend to be a little slow to get involved and, once there, question their competence as caregivers. They often feel helpless and uncertain. They don’t know what to do or how to begin. Personal tasks are particularly awkward, especially when it’s time to give Mom a bath.

Men are often reluctant to let others know that they are caring for a parent. They are particularly silent at work, fearful that revealing the situation will hurt their careers.

They are also less willing to get emotional support when they feel overwhelmed. They don’t talk with their friends about the stresses of parent-care or join support groups as readily as women do. Likewise, they are less likely to talk with a doctor or other professional about depression or anxiety, or to take medication for it. Instead, they turn to alcohol (bad), work longer hours (bad), or release their stress on a playing field (good).

However, there are aspects of parent-care that men do better than their female
When one parent is ill and the other is still able, everyone’s attention naturally turns to the patient, but don’t ignore your healthier parent—the caregiver. Your job is to help her so that she can do her job well.

Remember, her life has taken a dramatic turn. She has taken on enormous responsibilities. She stands to lose her mate and has already lost vital aspects of their relationship together.

You might not be able to extricate her completely, but you can lighten the load, be sure she gets a break, and offer emotional support.

Talk about the situation. Make a list of what jobs need to be done, which ones your parent feels that only she can do, and which ones others in the family or outsiders can do. Listen to her fears and needs, and help her understand the importance of taking care of herself and the ramifications if she were to become ill.

You might have to inch your way into this, taking over one small task and then another, or nudging her gradually toward community services and in-home help. Offer to take care of your father for certain shifts or to take over peripheral duties, such as home maintenance and bill paying.

Respect her desire to care for her spouse, but also be sure she gets away from the job occasionally.

Monitor her health, because she may be neglecting it now. Get her to eat well, sleep (which might mean moving to another bedroom), exercise, and see the doctor when necessary.

Helping your parent now will not only allow her to give her best to her spouse, but should also head off disaster. You do not want to find yourself with two ailing parents instead of one.

The Well Spouse Foundation (800-838-0879 or wellspouse.org) can help. It hooks members up with online and local support groups, and issues a newsletter.
We Welcome Your Views

HOW TO CARE FOR AGING PARENTS has tried to address the wide range of concerns and questions that caregivers face in as much detail as possible. But there is always room for improvement. Please let us know your thoughts on the book—advice that was helpful, questions that weren’t addressed, facts we might have missed—so that we can make adjustments and include your views in any future editions. You can reach us at careforagingparents.com. We look forward to hearing from you.

Virginia Morris is an award-winning author and journalist and a nationally recognized authority on eldercare. She testified before the Joint Economic Committee of the U.S. Congress. She has also appeared on Oprah, The Today Show, Good Morning America, The CBS Morning Show, Primetime, ABC World News with Diane Sawyer, NPR’s The Diane Rehm Show, Katie, and a host of other national media. Her previous book is Talking About Death. Morris lives in Sag Harbor, NY, with her family.

She is available for speaking engagements, media appearances, and consulting. She regularly gives keynote addresses and joins panel discussions addressing the needs of family caregivers, professionals, businesses, and employees. For more information, visit careforagingparents.com.
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We hope you enjoyed this custom preview from the book, How to Care for Aging Parents. To buy the full book, click here.
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