

ELDER CARE 101 - FIRST STEPS

Gather Information to Start Your Caregiving Journey

Caregiving for an aging parent, spouse, domestic partner or close friend presents tough challenges, especially when a crisis hits and responsibility descends upon you suddenly. Maybe your mother has fallen -- perhaps due to instability caused by prescription drug side effects -- and is hospitalized with a broken hip. Or your spouse has wandered off and gotten lost several times. Or a long-time friend and mentor has lost a lot of weight and rarely seems to leave home.

Caregiving descends upon us in all sorts of ways -- through sudden crises or a series of small but unsettling mishaps and warning signs. You may be the only person to step in or you may simply be the linchpin of a large network of family members and friends willing to help. Whatever the situation, you are not sure of the next step. Or even the first step.

Whether you are in the middle of a crisis and decisions have to be made quickly, or planning ahead for an elderly loved one because of unsettling warning signs, we can help you in a variety of ways.

Does your loved one need help? Warning signs ...

- Difficulty walking -- unsteady when standing -- recent fall(s)
- Poor grooming and personal hygiene -- soiled clothing
- Loss of appetite -- changes in eating / cooking habits
- Spoiled or outdated food in frig -- little nutritious food in home
- Diminished driving skills -- recent accidents -- near misses
- Loss of interest in activities once enjoyed
- Reluctance to socialize
- Difficulty concentrating ... poor judgment
- Memory loss -- forgetfulness -- confusion
- Mishandled medication(s)
- Persistent fatigue -- lack of energy
- Personality changes -- irritability -- sudden mood changes
- Unopened mail -- past due bills -- mishandled finances
- Poor housekeeping / home maintenance -- unsafe conditions

What kind of help does your loved one need? Are the problems undiagnosed but correctable? For example, prescription drugs interactions and other side effects, Vitamin B12 deficiency, dehydration and other treatable conditions are mistaken for Alzheimer's disease and other forms of dementia more frequently than most people realize. According to Consumer Reports on Health, "Any new health problem in an older person should be considered drug induced until proven otherwise." (To help determine if prescription drugs might be a source of your loved one's problems, visit our page www.Aging-Parents-and-Elder-Care.com/Pages/Prescription_Drugs.html.)

If your loved one's problems are not correctable, what living arrangements and nursing care plans are most appropriate? If they are able to remain in their own home, how do you figure out what kind of home care to arrange? Is assisted living preferred over nursing homes? What particular challenges does your loved one's disability pose? What is the best way to access community resources? How will you manage it all -- and still maintain a life of your own?

This article will walk you through the first steps -- whether you are dealing with Alzheimer's disease or another form of dementia, recovery from a broken hip, or trying to figure out Medicare benefits. It is intended as a primer -- a source of both information and comfort. Each caregiving situation is unique, of course. Your loved one's medical history, financial resources, personality, relationships with potential caregivers, proximity to services and other factors all determine the best approach to take. Some seniors may have prepared in advance for declining health and have the necessary documents and services in place; others may have delayed taking action because they always believed they had more time.

Whatever the circumstances, the information below will help you get started. Then, in our website, you will find several comprehensive checklists to help you with more detailed guidance -- (go to www.Aging-Parents-and-Elder-Care.com/Pages/Elder_Care_Checklists.html) -- and to help you feel more confident that you have not forgotten something important. Finally, our website includes links to a number of excellent specialty websites to help make it easier for you to find the information you need -- and to save you time.

So, here is our advice to caregivers:

- Take a deep breath. This may be the most important advice you receive throughout the caregiving journey. All along the way, remember to pause from time to time and collect your thoughts. Clear your mind and relax. It may be difficult, but it will help sustain your spirits and prevent you from sinking under the weight of caregiving burdens.
- Make sure you know the senior's date of birth and Social Security number. You will need this information to access many services.
- Collect information about medical providers. If you haven't done so already, gather details about your loved one's physicians and health insurance. Here is some of the information you will need:
 - Names, phone numbers and addresses of the senior's doctors, dentist and pharmacy (be sure to include complete details about any arrangements the senior has made for discount prescriptions).
 - Copies of health insurance policies and the front and back of all insurance cards; if your loved one is 65 or older, you will need a copy of his or her Medicare card. (Medicare has prepared a helpful online booklet, "Medicare & You 2006." To download it, go to www.medicare.gov/Publications/Pubs/pdf/10050.pdf. It includes a summary of Medicare's benefits; rights and protections; answers to the most frequently asked questions about Medicare, and information about Medicare's new prescription drug coverage.)
 - Make a list of all medications (prescription drugs, over-the-counter drugs such as aspirin, antacids, herbal remedies, nutritional supplements -- even daily multi-vitamins), dosage amounts and instructions for taking them (time of day, with food or between meals, etc.). Take this list with you to ALL of your loved one's medical appointments to help avoid dangerous prescription drug interactions.
 - Date and results of recent medical tests, including exams, x-rays, CT scans and MRIs.
 - Complete health history (also take this with you to all of your loved one's medical appointments). If possible, include major illness and medical conditions for your loved one's parents, brothers and sisters.
- Learn as much as possible about the medical condition afflicting the senior. Talk to his or her doctors (see "Important Note" on page 5). Conduct research on the Internet (start with our page, "Elder Care Resources," at www.Aging-Parents-and-Elder-Care.com/Pages/Elder_Care.html). Find reference books in the library. Contact related organizations and associations for information

about the disorder. Study the symptoms and progression of the disease so you can anticipate what might come next. (You will find a list of the symptoms for some of the most common health conditions that afflict the elderly on our “Symptoms” pages which begins at www.Aging-Parents-and-Elder-Care.com/Pages/Age_Dementia_Symptoms.html.) Find out about available treatments, experimental research and clinical trials. (We have included more information about clinical trials in our page, “Prescription Drugs and other Medications” at www.Aging-Parents-and-Elder-Care.com/Pages/Prescription_Drugs.html.)

- Call a family meeting. Try to get as many people as possible involved from the beginning. Early input from them will facilitate communication and decision-making down the line. Allow all family members a chance to express themselves and their feelings about what should be done. If possible, designate a person to be responsible for each task.
- Find out if the senior has the proper legal tools and documents in place. Has someone been appointed to take care of business and make health care decisions in case of temporary or permanent disability? Has the senior made clear their wishes for end-of-life care? If necessary, consult an attorney specializing in elder law. These are some of the documents you should help the senior prepare if they have not already done so:
 - Will
 - Durable power of attorney for finances
 - Durable power of attorney for health care
 - Living will
- Investigate your loved one’s health insurance matters. What kind of coverage do they have? Are they eligible for Medicare benefits or Medicaid? If so, are they enrolled properly? Do they have a long term care insurance policy in place? If so, what exactly does it cover? Do they have any coverage through a private pension plan or retirement package?

Because the wording in insurance policies can be confusing, we have prepared a glossary using words that are easy to understand. It also includes other terms related to long-term care at www.Aging-Parents-and-Elder-Care.com/Pages/Pages/LTC_Glossary/LTC_GlossaryA.html.
- Explore other available financial resources. What assets does he or she have? Do they own real estate? How much is their home worth? How much is in savings accounts, IRAs, stocks and bonds and other investments? What is his or her monthly income from Social Security, other government programs, private pension plans, CDs, other bank accounts, annuities and investments? You can begin to document these and other important information for and about your loved one by using the free personal and financial organizers available through our sister website, Today’s Seniors, at www.TodaysSeniors.com/pages/Organizers.html.
- Take a crash course in community resources. Find out about senior centers and adult day services in the senior’s area. What are the best home health agencies around? What meal delivery and transportation support options are available? Assess the senior’s skills and determine the resources you need. (Once again, we have included in our website a variety of checklists and links to Internet-based resources to help you investigate these matters.)
- Even if this is an acute crisis likely to pass, start gathering information about assisted living facilities and other long-term care options. When the time comes, you will want to be able to offer the senior a range of options to choose from. (Once again, you will find the information you need to start in our website.)
- Recognize that loss of sight, hearing loss, memory loss, confusion, incontinence and depression are not normal aspects of aging. In many, if not most cases, these are treatable conditions. (They could very well be the result of prescription drugs interactions or drug side effects.) Failure to identify these conditions as being treatable could place elderly patients at risk of unnecessary functional decline.

- If your senior lives in an assisted living facility at some distance from you, one of your concerns will be replenishing your loved one's health care supplies at a reasonable price. While you can hire a personal shopper, it may be less expensive and just as reliable for you to shop online and have the supplies delivered to your senior. Our website includes a wide variety of health care products and supplies for first aid, incontinence, wound care, foot pain relief, diabetes, canes, and handicapped equipment such as medical bed rails frames, walkers, shower accessories and grab bars. (For more information, visit our "Daily Living Resources" page at www.Aging-Parents-and-Elder-Care.com/Pages/Daily_Living.html.)
- Consider hiring a care manager. These professionals are trained to quickly assess the overall situation, make recommendations about needed services and, if necessary, coordinate community resources and hire and manage paid caregivers. You can find more information on our page www.Aging-Parents-and-Elder-Care.com/Pages/Elder_Care_Managers.html.
- Consult with everybody and anybody. Talk to friends, neighbors, acquaintances -- anyone with experience in caring for an elder. In reaching out you will assemble a mosaic of information about how to proceed and what to expect down the line. You will learn that others have been there before and found their way through -- though sometimes with great difficulty and sadness.
- Talk to your senior. This isn't always possible, but it's best to allow them as much independence as circumstances permit. Remember that the caregiver's role is to help them maintain as much control over their lives as feasible, not take it away; this includes allowing them to make their own decisions unless the decisions become harmful to them. The more you can consult with them, consider their desires, and truly respect them, the smoother the transition in your relationship will be.
- Make sure that everyone on the caregiving team -- whether they are family members, friends or professionals -- has the information they need to perform their responsibilities. Make a list of emergency numbers, family contact numbers and other items and distribute it to those who might need it. Family members should know how to locate legal, financial and medical documents like durable powers of attorney, living wills, investment account statements and health insurance policies in case of emergency.
- If the senior is still living at home, make sure you and others in their inner circle have keys to the residence in case of emergency.
- Keep good notes. Whenever you talk to a doctor, lawyer, insurance company, service agency, government office or advocacy organization, write down the date and the name of the person you spoke with, contact information and the substance of the conversation. Keep separate files for different areas of concern -- financial topics, medical affairs and so on.
- Even though this may sound unnecessarily pessimistic, never assume that the professional and medical personnel who are helping you with your loved one will do what they promise. If you don't actively follow-up, you may set yourself up for disappointment. While they made their promises with the best of intentions, these professional people are extremely busy and have other people to care for in addition to your loved one. They may honestly forget a commitment made to you. Bottom line -- the more you become involved with the care and other affairs of your loved one, the more satisfied you will be with your caregiving experience.
- Acknowledge your own feelings of loss, anger, shock and confusion. Perhaps you realized this moment was coming, perhaps not. In any event, you are likely to find unsettling emotions bubbling through the surface. Allow yourself time to experience them. Write them down in a journal. Take a long bath. Find a quiet corner and close your eyes. Take care of yourself, too.

Important Note

When you visit a doctor, dentist, hospital, lab, or other health care provider, you are often asked to sign a form stating that you have received the provider's Privacy Statement. The form will also usually include an Authorization section that gives the provider permission to share your medical information with other health care providers.

Patient privacy has become very important in our society, but its rules can be very frustrating. For example, if your loved one has a medical emergency, you usually won't be able to get any information about him or her, even if your loved one is your spouse. When you ask, "Why not?," you'll hear that you can't be told because of HIPAA. That's the federal law that governs patient privacy. In our opinion, HIPAA's patient protection rules are a good example of the best of intentions gone bad.

HIPAA works very well when it prevents unauthorized people from learning about your private medical information. For example, a drug company cannot get information about any illness you have so they can try to sell you their latest "miracle" cure. And, telemarketers can't get your personal medical information so they can sell you an herbal concoction that's guaranteed to cure everything from warts to hair loss to flat feet -- and more.

Where HIPAA doesn't work is that your spouse and other members of your family are automatically **excluded** from your list of authorized people. Very few Privacy Authorization forms have a space where you can indicate which family members do have your permission to share your medical information. In each case, you need to ask how you can give permission to share your information with the people of your choice.

As just one example of the difficulties caused by HIPAA, we know a doctor in Florida whose husband was hospitalized in California. The hospital would not tell her anything by phone even though he was temporarily unconscious and could not give the hospital permission to talk to his wife.

While a few health care professionals may sometimes bend the rules slightly for family members with the same last name as their patient, you can't count on it. Married daughters with different last names can face an impossible hurdle.

Is there a solution? YES! In fact, there are two.

First, don't wait until you are faced with a medical emergency. Every time you and your loved one visit a doctor, hospital, medical lab, etc., ask them for whatever form your loved one has to sign for them to talk with you about his or her medical affairs. **Important note:** Each form your loved one signs applies only to that particular health care provider; if your loved one has several health care providers, he or she will need to sign a permission form for each one of them. And, if you have brothers or sisters, be sure to include their names on each permission form your loved one signs.

Second, if your loved one has any of these documents,

- Durable power of attorney for health care
- Living will
- Trust(s)

and he or she is still mentally competent, each document should be reviewed at the earliest possible date by an attorney who specializes in elder law to be certain that the necessary HIPAA language has been included. If it isn't there when it becomes necessary to utilize the document, doctors and lawyers won't be able to communicate with each other, and it is very likely that your loved one's instructions in those documents will not be followed.

Speak with an attorney who specializes in elder law. Check the yellow pages in your local telephone directory, or go to the National Academy of Elder Law Attorneys' website at www.naela.org. On their home page, you'll find a link in the upper left corner (just below their logo) that will help you locate an elder law attorney.