

Second  
Opinion

*Caregiver's  
Diary and  
Resource  
Guide*



*Second Opinion* is the award-winning PBS health series.

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Produced by WXXI Public Broadcasting and University of Rochester Medical Center, *Second Opinion* improves doctor/patient communication and empowers viewers to take charge of their healthcare.

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# Using this booklet

Use this Caregiver's Diary and Resource Guide to help you manage your loved one's health care and find the resources you may need as a caregiver. Keep your loved one's medical information at your fingertips and handy during doctor's visits and phone calls. Be sure to update the information as anything changes.

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# Caregiving: A Mission from the Heart

By Peter Salgo, M.D.

*Second Opinion* Host

Specializes in Intensive Care Medicine

NY Presbyterian/Columbia University



When I was in medical school, no one talked about caregivers. In fact, no one really focused on what happened to patients after they left the medical setting, whether a doctors' office, clinic, or hospital. Times have changed. More and more of our patients require daily care (often complex and physically demanding care), in settings outside the doctor's office.

More than 50 million Americans provide care for a chronically ill, disabled or aged family member or friend during any given year. You know the caregivers among us. These caregivers are our friends, family, neighbors and coworkers. They are the 46 year-old woman caring for her widowed mother who does not live with her. They are the seniors, aged 65 and older, caring for their parents, or their aging spouses (representing 30 percent of all caregivers). They are often bearing overwhelming burdens that they do not share with us. And many are desperately in need of help.

The value of the services caregivers provide for "free" is estimated to be \$306 billion each year. That is almost twice as much as is actually spent on "traditional" homecare and nursing home services. Employers lose as much as \$34 billion dollars a year in productivity, while caregivers themselves spend an average of \$5,531 per year out of pocket – more than 10 percent of the median caregiver income (\$43,000/year).

There is still another cost. More caregivers in the United States describe their health as only "fair" or "poor" than do people who are not caregivers. And, of those caregivers, nearly six in 10 say their health is the worse for their caregiving activities.\*

If this seems to paint a bleak picture of caregiving in America, it's worth considering what caregivers receive for their investment in others. They reap some of the greatest rewards humans can experience. They provide love to those in need. They provide comfort to those without. They get to spend time with those for whom they care.

This booklet is part of the "*Second Opinion* for Caregivers National Education Campaign," an initiative to help these quiet, determined heroes get through their days.

Many caregivers, caregiver and patient advocates, and healthcare professionals have helped us unearth some of the key, real-life caregiving issues. We have addressed them head-on in this booklet with articles of advice and support, as well as worksheets and checklists to make record keeping easier.

A lot has changed in medical practice over the years, but the basics remain the same: compassion, care, concern for the well-being of all. All of us at *Second Opinion* salute you, the caregivers of America, and recognize the immense effort you expend each day to improve the lives of those you love.

A handwritten signature in blue ink, appearing to read 'Peter Salgo, M.D.', with a long horizontal line extending to the right.

\*The Evercare Study of Caregivers in Decline (9/06, National Alliance for Caregiving and Evercare)



**BlueCross BlueShield  
Association**

An Association of Independent  
Blue Cross and Blue Shield Plans

## *A Message from the Blue Cross and Blue Shield Association*

On behalf of the 39 independent, community-based Blue Cross and Blue Shield companies, the Blue Cross and Blue Shield Association is proud to sponsor the award-winning *Second Opinion* program on PBS for the fourth year in a row. This ground breaking series empowers viewers with information on managing their own healthcare and helps them make more informed decisions about treatment options.

The Blue Cross and Blue Shield System strongly believes that everyone should have health insurance. According to the most recent data released by the U.S. Census Bureau, 45.7 million people don't have health insurance. We must make addressing both rising healthcare costs and extending coverage to everyone a national priority.

In 2008, the Blue Cross and Blue Shield companies collectively unveiled a comprehensive, five-point plan, The Pathway to Covering America, to improve healthcare quality and affordability, and to address the millions of Americans without health insurance. This proposal is based on nearly 80 years of experience as leaders in the health community and outlines key recommendations for addressing the number of uninsured, including:

**1. Encourage research on what works.**

America needs an independent institute to support research comparing the relative effectiveness of new and existing medical procedures, drugs, devices and biologics.

**2. Change incentives to promote better care.**

The incentives in our system must be changed to advance the best possible care, instead of paying for more services that may be ineffective, redundant or even harmful.

**3. Empower consumers and providers.**

We must give consumers and providers the information and tools they need to make informed decisions. This starts with information systems to manage personal health records. In addition, consumers need to know how much they are paying and what they are getting for it.

**4. Promote health and wellness.**

We must promote healthy lifestyles to prevent chronic illness and work aggressively to help patients with chronic illnesses manage their health.

**5. Foster public-private coverage solutions.**

We need to tailor our coverage plans to capture the diversity of the uninsured population so that no one gets "squeezed out" by cost, "misses out" on available government assistance or "opts out" because they do not think they need coverage.

There is no simple solution to healthcare reform, but we believe our five-point plan can go a long way toward improving healthcare quality and affordability. Meaningful change to our nation's healthcare system will require the collective efforts of insurers, hospitals, physicians, policymakers and others. As healthcare leaders for nearly 80 years, the Blues are committed to building a well-functioning and totally integrated healthcare system based on proven clinical outcomes and economic value that will better serve the needs of all consumers – safely, efficiently and consistently.

*Support  
and  
Advice*

# The Challenge of Caregiving



By Barbara E. Moscovitz, MSW, LICSW

Coordinator, Geriatric Social Work

Massachusetts General Hospital Geriatric Medicine Unit

For many, discussing the possibility that a parent or spouse may need care later in life is too frightening and difficult to consider until a crisis occurs and there is no choice. It is understandably complicated for many adult children to speak with their parents about their wishes in the event of illness; however many families have learned that the benefit of open and honest discussion is a critical and often life-changing process.

Whether in advance, as is ideal, or once a loved one needs care, it is important to start the conversation and get organized.

*The core components of caregiving are:*

- Communication among all members of the family
- Involvement of the patient as long as possible in decision making
- Completion of basic legal and estate documents
- Linkage to community resources and health care providers

## How to begin the discussion?

The most important step to take is the first one; *gather the elder and family members who will be involved in care and begin talking.* The key is to stress that the reason for talking openly and honestly is to ensure that the elder's wishes are honored in the event that he or she may not be able to speak for themselves in the future. It is a gift if a parent or spouse can express wishes and prefer-

ences to the family so that there is a map for others to follow.

*Some issues to consider in the first phase of discussions:*

- Does the elder have a preference about where to live? At home with care? In a facility near a family member?
- Are there values/religious beliefs/wishes that are important for others to know if they are making decisions on behalf of the elder?
- Have important documents been completed? For example, Advance Directives, Will, Durable Power of Attorney? For many, it is advisable to meet with a lawyer who specializes in legal planning for elders.

Initial discussions enable caregivers to proceed with care and clarity. It's important to remember that caregiving represents many emotional challenges for both the caregivers and care-receivers.

Care-receivers who are slowly or rapidly losing their capacity to care for themselves may feel a profound loss of control and autonomy. Many express feelings of helplessness, fear and sadness as they adjust to their changing life.

It is difficult for an adult who has raised a family and has been independent to need help. Similarly, adult children and spouses must adapt to their new roles which may include new responsibilities, opportunities and stressors.

Families and patients can survive and even thrive in a caregiving setting; however it's key to bear in mind that caregiving is a learning process and involves many factors, phases and emotional challenges.

All family members need to communicate, share responsibility and contribute to the experience. These efforts take time to achieve, and each family will find their unique way of succeeding.

# The Rewards of Caregiving



By David Latshaw

Caregiver to wife, Barbara

Do I have positive feelings about caregiving?  
You bet I do!

We are in the 18th year of dealing with my wife Barbara's dementia. By "us" I mean Barbara's sister, Fritzie, and our daughter, Becky; it has been a team effort from day one.

As a guest on the *Second Opinion* panel discussion on caregiving, I was asked, "What do you have say to someone just realizing they face a caregiving situation?" My answer was something to the effect of, "I hope you are surrounded by a loving family."

That is a good part of why I have very positive feelings about my role as a caregiver. Separate from that, I believe a good marriage is the big difference. This year, we celebrated our 57th anniversary – and they were all good years. This is not to say we didn't have disagreements, just none of a serious nature. We never let the anniversary pass without some one-sided conversation about the many years and good times, as well as showing her cards from family and friends.

Barbara does not speak, which is a real downer. There is no indication by facial expression what she understands. She is not able to do anything on her own other than open her mouth and eat – pureed food, of course. A limp is the only sign of pain from an infected foot.

One of the more enjoyable things of my life is feeding her. At times, she seems as a child and it cannot be helped but smile at her. Her eyes seem to be on mine constantly, except if I'm too slow with the next bite of something especially good to her. Then her eyes move to the dish and she raises her head a little.

It is clear some things we say are understood and she will comply with some direction. As a child will do, some things are simply ignored, whether by choice or otherwise, who knows?

One of the last functions she would perform on command was with our son, Todd, who lives out of state. When visiting, he would look at her straight-on and say, "Wink if you love me." She would immediately wink. This gradually diminished until there was no response. Now, frequently I look at her and wink, repeatedly. Her eyes move from my winking eye to the other and back possibly a dozen times. She knows what's happening but can't respond until, finally, she will wink both eyes; her best effort.

I know what it's like to change messy diapers. It is something I didn't do with our children. I didn't want to do it and Barbara apparently didn't think I needed to for she never pressed. It is no problem with me today. Time marches on.

Many of my good old friends will say to me, "I don't know how you do it. I couldn't." I say, "Of course you could and would," but I know there are exceptions.

They go so far as to say I'm a saint. I smile at that and say to myself, "Yeah, St. David sounds neat; St. David of what? St. David of the Ordinary." I'll accept that.

In memory of Barbara Latshaw

# Caregivers a Source of Strength for Each Other



By Nina Mottern, BSN

Geriatric CC/Dementia Care Manager

Canandaigua VAMC/Rochester VA

I recently had the privilege of collaborating on a project with some of the caregivers that care for our veterans. The project was called, "The Many Faces of The Caregiver." Caregivers were given an opportunity to share their experiences with each other. Each experience was unique, as was each caregiver and loved one. It was quite apparent that, without the support of their caregivers, the veterans' lives would be drastically different and without quality.

The caregivers said they were humbled by each other's experiences and all marveled at the resolve of each situation. I was overcome by the depth of the love and commitment that was so clearly evidenced. The shared experiences were rich with all that speaks of strength and purpose. Each contributor voiced the sense of validation experienced by being able to put into words what they learned along the way and what they carried in their hearts.

During the event, the caregivers offered support and successful strategies to each other and I'm sharing some that I overheard here so maybe they'll help others:

- Often times, when out in the community, a gentleman with Alzheimer's Disease would make inappropriate comments to others. Rather than curtailing future outings, his wife, and caregiver,

had small business cards printed that read "My husband has been diagnosed with Alzheimer's Disease. If he has said something to offend you, I am sorry". With this intervention, the couple could continue to go out into the community and the caregiver no longer felt isolated.

- When a veteran insisted on visiting his parents and wanted his wife to give him the car keys, she "reminded him" that they were not at home that day and they could plan the trip tomorrow.
- When a caregiver was reprimanded for not visiting more often (she visited every day), she told her mom that she understood how much she always enjoyed company and she would visit more often. The remainder of the visit was quite amiable.
- When the veteran was agitated because "the children next door" were making too much noise, the caregiver agreed to speak with them immediately. Things soon quieted down to the loved one's satisfaction.

Offering reassurance in the context of the loved one's reality is okay. Some folks feel it is dishonest and go to great lengths to "re-orient" their loved one in ways that are no longer cognitively possible. One suggestion I was able to make to a caregiver pertained to a nightly argument. At bedtime, her husband would want to go tuck in the kids (something they'd done together every night when their four children were young). This resulted in an uncomfortable situation nightly when she had to explain that the kids were grown and living elsewhere. I suggested she simply answer, "We already did." Her husband accepts that answer and the nightly argument has been replaced by a gentle reminder.

# Navigate the healthcare system with a project management approach



By Dianne Savastano, MBA, B.S. Nursing  
Principal of Healthassist Corp.

When managing a health care crisis for yourself or a loved one, you may well be facing the challenge of your life. Navigating the complexities can be overwhelming, even to those who understand how the system works.

Take the example of Anne, a nurse whose father was diagnosed with two types of cancer within the space of a month. His case required the services of 18 different entities. Anne was the only one responsible for overseeing the big picture. Even with her background, she had a hard time keeping track of all the people participating in her dad's care. The potential for something to fall through the cracks was huge.

You may find yourselves in Anne's position. Many caregivers work full-time and must juggle careers, family and their own needs while caring for loved ones.

Here are a few techniques to help you take on this challenge with confidence:

## 1. Define the team

First, list the members of the medical team, such as the primary care physician, specialist physicians, hospitals, home health agencies, insurance, and their contact numbers, and note who does what. The medical team is one half of the picture. The caretaking team of family, friends and neighbors is just as crucial. Note the people who offer rides to appointments, run errands, and check on the patient.

## 2. Get organized

Create a calendar of upcoming medical appointments that you can share with your primary care physician and the caretaking team.

Before a doctor's appointment, make sure you have all necessary paperwork with you – such as referral forms, copies of diagnostic tests, and medication lists. People often have to reschedule appointments with specialists because they are missing an important piece of paper.

## 3. Set objectives and target dates

One of the most anxiety-provoking aspects of an illness is unpredictability. However, if you are able to set clear objectives, you won't lose focus when the unexpected happens.

One way to avoid setbacks is to rely on your calendar. When your doctor orders a diagnostic test, such as an x-ray or blood test, find out how long it takes to receive results. Then mark that target date in your health care calendar. If for some reason your physician does not call you within the timeframe, you can follow up with her. Ask for a written test report.

## 4. Communicate regularly with the team

Many people assume their primary care physicians and specialists regularly communicate regarding changes in their condition and treatment. Unfortunately, even the most conscientious doctors have trouble keeping up with news regarding each and every patient. As a health care project manager, you can stay in control by communicating with providers and insurers each time something changes. For instance, in Anne's case, when her father was diagnosed with the second cancer, she alerted all his doctors so they could confer and prioritize treatment.

By following these powerful steps, you'll be able to navigate our complex health care system and be assured of a better medical outcome.

(Note: see Caregiver's Diary beginning on page 35)

# Communicating with Doctors: A Caregiver's Perspective



By Beth Witrogen, caregiver to husband and parents  
Author and journalist on aging and wellness

For two years I cared for both parents, Mel and Elaine Witrogen, while they were simultaneously terminally ill 1,200 miles away. A decade later I cared for my husband, Robert. Throughout these times the biggest challenge, besides the emotional, was communicating with medical professionals, not just to get the proper care, but also to feel that I was being seen and heard as a caregiver. These are tips that I used when communicating with their doctors:

- First, start using a notebook (or booklet like this one) to track important information.
  - Keep doctors' names and phone numbers on the first page as well as a list of all medications and treatments.
  - Write the dates and times of each call or appointment, the doctor's name and questions you have in advance of that conversation.
  - Record the results of the call/visit. Use a tape recorder if you wish.
  - Don't write on scraps of paper. Use the notebook.
- Don't hesitate to call any of the doctors or their nursing staff. You are not bothering them. Someone needs to advocate for your loved one.

- Ask for clarification as many times as you need it. Understanding the doctor's responses is essential to good communication and compliance; the doctor will wait for you to write down instructions (but be respectful of time and find a good balance).
- Ask the doctor for printed materials about your loved one's condition. It's also okay to ask for the doctor's dictated notes. Every primary caregiver has a right to obtain medical records.
- If you want more information, ask for reliable sources especially on the Internet.
- Other members of the patient's health care team, such as nurses, social workers and pharmacists, can be good sources of information. Talk to them, too, especially in a hospital or care facility.
- Don't accept receiving less of an answer or assistance than necessary from medical staff (including those who make appointments). My experience has been that patients are fairly shy about speaking up for themselves. You may need to be the one who advocates for your loved one.
- Remember that the doctors are not gods, and do the same things we all need to do every day. Don't expect more than is humanly possible from them, and don't be too intimidated by their expertise to be the patient's advocate. They truly want to serve and help.
- Thank the doctor. I can't say this enough.

# Communicating with Doctors: A Doctor's Perspective



By Lisa Y. Harris, M.D.

*Second Opinion* Panel Regular

Primary Care Physician

Temple Medical, Rochester, N.Y.

A caregiver may be defined as one who provides for the needs of others. Traditionally, in the medical sense, we think of caregivers as those who provide for the healthcare needs of others. For the purposes of this article, we can consider caregivers or care providers as individuals who provide ancillary support to friends or loved ones.

From a doctor's perspective, caregivers have the opportunity to obtain a wealth of information that is invaluable to the medical provider. This includes information such as how well the patient sleeps, how often and how much they eat, and if they are able to perform any of the activities of daily living. Caregivers can answer, "How do they interact with their environment or with individuals?" All of this data can help to shape the medical plan of care.

In the past, clinicians were able to obtain information during the office visit but, unfortunately, many primary care doctors no longer have the luxury of a lengthy office appointment. The question is, how can we maximize the visit so that all parties are informed and in agreement with the care plan?

*There are some things the caregiver can do to aid this communication I'll call it my wish list:*

1. Be observant. Take note of the little things and write down any areas of concern or deviations from the baseline. (*See page 40*)
2. Be organized: a rambling dissertation on the minutia of life is not beneficial to the doctor. Organize your concerns into topics such as eating, bowels, sleep, behavior, etc.
3. Fax or mail your concerns to the office before the visit and notify the clinician that you are doing so.
4. Plan to come to the office visit. So often, patients either lack insight of their status or are unable to communicate factual information. For example, demented patients report their memory is fine; sleep apnea patients say they don't snore.
5. Have one or two top-priority items that you would like to address at the visit. Remember the clinician also has an agenda and time constraints.
6. Don't be afraid to ask questions. (*See page 30: "Questions to ask the health care provider."*)
7. Be open and honest. It's okay to admit you need help or a break. Clinicians often get caught up in the clinical aspects of care and may neglect the social aspects. There are many resources available to you. All you have to do is ask. The only bad question is the one that remains unasked.

Caregiving can be a rewarding experience. Working together with the health care provider can enhance the quality of your interaction.

# Six Steps to Getting Help

By Suzanne Geffen Mintz  
President and Co-Founder  
National Family Caregivers Association  
[www.nfcacares.org](http://www.nfcacares.org)



Despite the fact that family caregivers are drowning in responsibility or are really confused about what the next step ought to be, they often respond “no thanks” when help is offered.

Asking for and accepting help is a complex issue. Obviously you first need to admit that having some help will make a real difference in your loved one’s quality of life, and therefore yours as well. Then, you need to define what help you need. It doesn’t have to be an overwhelming task, but rather just a way to organize the thoughts and information you already have.

## *Here are six steps to getting help:*

- 1. Recognize that caregiving**, like any job, is made up of lots of individual tasks, not all of which are of the same importance. The challenge is to know which take more time, skill or effort than others.
- 2. Recognize that asking for help is a sign of strength.** It means you truly have a grasp on your situation and have come up with a proactive problem-solving approach to making things easier and better.
- 3. Create a list of the tasks that need to get done in any given week**, or at least those you are most concerned about. When you see how long the list is you’ll quickly understand why you are so tired and don’t have time for yourself.
- 4. Group your tasks into categories** such as personal care tasks for your loved one, transportation, household chores, etc. You can group your tasks into only a few broad categories, or many specific ones.

There’s no right or wrong way. It’s all a matter of personal preference.

- 5. Write down your caregiving worries.** Seeing them in black and white helps diffuse some of their emotion. It also allows you to think more rationally about your concerns and understand how getting help with some of your tasks might lessen the stress. It can provide the basis for deciding which tasks you might ask someone you know to help out with, which you are willing and able to pay someone else to do, and for which there might be a public program.
- 6. Share your lists with someone you trust** before you actually reach out for help. The intent is to first get comfortable with the idea of talking about your need for assistance and hopefully get some encouragement and good ideas in the process. Then take a deep breath and actually ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small. Don’t get discouraged if you get rejected at first. It sometimes takes perseverance. Just remember—the effort is worth it because the goal is better care for your loved one and yourself.

*(Note: See “Action checklists for Family Caregivers and Those Who Care About Them,” page 28.)*

## *Places to get help*

ARCH National Respite Network  
Eldercare Locator  
Lotsa Helping Hands  
National Respite Locator Service

(See full list of caregiver resources starting at page 47).

# Legal Issues to Talk About Now



By Kathy Kelly, Executive Director  
Family Caregiver Alliance

[www.caregiver.org](http://www.caregiver.org)

When a family member is diagnosed with Alzheimer's disease or another disabling health condition, it's easy to feel overwhelmed by the many legal and financial questions that arise. You should consult an attorney as soon as possible because more options are available while the patient is still able to help make decisions.

It is especially important for caregivers to find an attorney who has the appropriate expertise. Attorneys advising caregivers on planning for long-term care should have knowledge of the following areas of law:

- Medicaid (Medi-Cal) laws and regulations
- Social Security
- Trusts (special needs trusts)
- Conservatorships
- Durable Power of Attorney for health care and asset management
- Tax (income, estate and gift) planning
- Housing and health care contracts

Some attorneys are certified specialists (such as in elder law, taxation or estate planning). In some cases, such as accidents, more than one attorney may be needed.

It's helpful to have a clear idea of what you'd like to gain from an attorney and learn as much as possible before meeting. For example, individuals who are interested in a health care directive may wish to think about the type of life-sustaining procedures they would want used in the case of a serious illness. It may also be helpful to identify a first, second and third choice of family member or trusted friend to make personal health care and financial decisions in the event the patient becomes unable to do so.

Other issues to discuss before the appointment include:

1. The management of the person's financial affairs during his or her lifetime. Options for managing assets include:
  - Durable Powers of Attorney;
  - Revocable living trusts;
  - Designation of a representative payee; and
  - Conservatorship (or Guardianship) of the estate and of the person.
2. The management of the person's personal care: medical decisions, residence, placement in a nursing facility, etc.
  - Is the person planning to stay in his home?
  - Is this feasible, both physically and financially?
  - Is he thinking of moving to a retirement facility?
  - What level of care is provided?
  - Is it a rental or a "buy-in" arrangement?
  - Is a move to a nursing home probable?
3. Arranging for payment of long-term health care: use of private insurance, Medicare, Medicaid (Medi-Cal in California) and Supplemental Security Income (SSI) when applicable. First look into the availability of private insurance to cover long-term care, whether at home or at an assisted living or skilled nursing facility. Also examine the government benefit programs that may help pay for care:
  - Medicare
  - Medicaid or Medi-Cal
  - Supplemental Security Income (SSI), and
  - In-Home Supportive Services (IHSS).
4. Preserving the family assets: ensuring that the patient's spouse and any disabled family members are adequately protected; and
5. The distribution of the person's assets on his or her death. (If the person has a disabled spouse, child or other family member that they wish to provide for, special arrangements need to be made).

## Items to Bring to the Consultation with an Attorney

1. List of major assets (real estate, stocks, cash, jewelry, insurance, etc.);
2. Any documents of title (e.g., copies of deeds, stock certificates, loan papers, etc.) which show who the asset owners are and how title is held;
3. Contracts or other legally binding documents;
4. Lists of all major debts;
5. Existing wills or Durable Powers of Attorney; and
6. Bank statements, passbooks, CDs—again showing who the owners are and how title is held.

# Conversations and Priorities

By Patricia Bomba, M.D.

Vice President and Medical Director,  
Geriatrics, Excellus BlueCross BlueShield



My life's work serving seniors and their families prepared me to act as the caregiver for my mother who died in our home Dec. 16, 2007. When I embarked on this journey, I viewed it as my final gift to my mother. In reality, it was her final gift to me. It was my privilege to care for her and ensure she was able to "Write her final chapter."

Adult children can help their parents and allow them their independence and dignity. Begin by having honest conversations, early and often. Understand what is important to them. Be realistic. Most importantly, care for yourself so you can be there for your loved one.

Here are my tips to help you achieve a balance among competing responsibilities.

- 1. Take care of yourself.** If you don't take care of yourself, you can't take care of others.
- 2. Talk early and often with your parent.** Many older Americans are private about their personal lives. Initiate the conversation by discussing how you're planning for your own future, or elicit a doctor's help in starting the conversation. Elderly people often are more receptive to their doctor's promptings about living wills and health care proxies than they are talking about them with their children. Once prompted, they will act.

- 3. Don't make promises you can't keep.** Most people want to age in the place they call home, but that's not always feasible. Ask your loved ones what their goals are. Talk about what can be done to help them age gracefully at home as long as possible. Ask who they would trust if they lose the ability to make decisions.
- 4. Remember your spouse.** Don't feel guilty about taking time to be with your spouse and children.
- 5. Use humor.** To get my mother to use her walker, I told her, "If you fall and break your hip, my reputation as doctor will be shot."
- 6. When others ask what they can do, take them up on it.** Have a list ready.
- 7. Achieve a balance of what your parent can do and what you can do for them.** My mother and I had a routine every Saturday where I was her secretary. I wrote out her checks but she was still making the decisions; I knew her bills were being paid on time.
- 8. Acknowledge the efforts of siblings who have the day-to-day care.** A simple thank you goes a long way. Even if you're at a distance, can you make doctor's appointments or arrangements for help in your parent's home, transportation, or Meals on Wheels? Make frequent phone calls to your mom or dad; older people are often lonely.
- 9. Use community resources.** Many local non-profit organizations and government agencies are dedicated to helping both seniors and their caregivers. For more information on advance care planning, palliative care and end-of-life care or to contact me, visit:  
[www.compassionandsupport.org](http://www.compassionandsupport.org).



*Action  
Checklists  
and Tips*

## Action Checklists for Family Caregivers & Those Who Care About Them

If you're a caregiver who needs help or if you're a friend who wants to provide it, use these handy checklists to help create an action plan.

Source: National Family Caregivers Association [www.nfcacares.org](http://www.nfcacares.org)

### Help I need as a caregiver:

- A ride to doctor appointments
- Someone to mow the lawn and shovel the snow
- Insurance forms filled out and filed
- Dinners prepared
- A shoulder to cry on
- The house cleaned
- The shopping done
- Help with paying the bills
- A weekend away
- A regular home care aide
- Someone to ask how I am
- More information on available resources
- A neighbor or two I can call in an emergency
- Some quiet time alone at home
- A handyman
- A sitter for [my spouse/parent/child]
- Understanding that we're the same people we used to be but our family's needs have changed
- Pick up prescriptions and other healthcare items
- Help with car repairs
- A night out with friends
- Other help I need:

### Help I can offer to a caregiver:

- Dinner and movies on me
- A regular ride at a pre-assigned time
- A meal prepared [       ] times a week
- A lawn mowed/a driveway shoveled
- Help with insurance or other paperwork
- A shoulder to cry on
- A maid brigade once a [       ]
- Grocery shopping every [       ]
- A [\$       ] check
- A prearranged weekend get away
- Coordinating a volunteer team to help out with specific caregiving tasks
- A weekly phone call
- Resource research
- My availability and desire to help out when necessary
- Taking [       ] out for a few hours
- A couple of hours of my tools and time
- Some of my time to stay with [       ]
- A real desire to be your friend, to stand by you and to understand as best I can how to participate in your changed life
- Run errands
- A pick-up at the garage and an offer to be a chauffeur for a day or two
- Other help I can offer:

## Questions to ask the health care provider

By Beth Witrogen, caregiver to husband and parents

Author and journalist on aging and wellness

### **About the disease or disorder:**

- What is the diagnosis?
- What caused this condition?
- Can the condition be treated?
- How will this condition affect his/her overall health now and in the future?
- Should I watch for any particular symptoms and notify you if they occur?
- Should he/she make any lifestyle changes?

### **About tests:**

- What kinds of tests will he/she have?
- What do you expect to find out from these tests?
- When will we know the results?
- Does he/she have to do anything special to prepare for any of the tests?
- Do these tests have any side effects or risks?
- Will he/she need more tests later?

### **About treatment:**

- What is the treatment for this condition?
- When will the treatment start, and how long will it last?
- What are the benefits of this treatment, and how successful is it?
- What are the risks and side effects associated with this treatment?
- Are there foods, drugs, or activities that should be avoided while he/she is on this treatment?
- If the treatment includes taking a medication, what should the patient do if a dose is missed?
- Are other treatments available?
- Where can I go for more information?

## Questions to ask health care provider's office

Source: National Family Caregivers Association

[www.nfca cares.org](http://www.nfca cares.org)

### **About How the Doctor's Office Works**

- What days/hours is the office open?
- How are medical emergencies handled?
- When is the best time to reach the doctor by phone, fax or e-mail?
- Which method of communication does the doctor prefer?
- Who can answer questions if the doctor is not available?
- Who can I call after hours or when the doctor is away?

### **Regarding the Costs of Medical Care**

- What private insurance plans do you accept?
- Do you accept Medicaid/Medicare assignments?
- What costs are covered by Medicaid/Medicare? Supplemental insurance?
- What costs are not covered by insurance?
- Approximately how much can I expect to pay in the long run for treatment?

### **Regarding Discharge Planning**

As part of the discharge planning process, many issues related to the patient's care need to be resolved. As soon as you know your loved one is going to be admitted to the hospital, find out who is

in charge of the discharge process and arrange a meeting to gather specific answers to the following questions.

- Where is the patient going to go after discharge? (Return to the previous setting? Go someplace else temporarily? Move permanently to a new location?)
- Who will provide additional home health care if it is needed?
- Does the patient need any home health equipment? What kind?
- Do physical and/or occupational therapy visits need to be arranged?
- What additional services may be needed and for how long (e.g., Meals-on-Wheels, hospice care, housekeeping, etc.)?
- What paperwork needs to be processed to get these services lined up?
- How will the added expenses be paid for?
- What additional skills do you need to learn so you can care for your loved one properly?

## Home Health Care Tips

Source: National Family Caregivers Association  
[www.nfcacares.org](http://www.nfcacares.org)

Homecare is a general term that represents a wide range of community-based services to support someone that is recuperating from an acute situation, such as a hip fracture, or services needed by persons with on-going chronic conditions, such as stroke or cerebral palsy. The skills and duties of home care personnel vary, but all have one thing

in common—they make it possible for care recipients to remain at home in a safe environment and in some cases have more independence than they did before. In the process, they also provide family caregivers with a chance to replenish their depleted physical and emotional reserves.

### Homecare personnel include:

- *Registered nurses (RNs)*—that provide skilled medical care, including giving medications, monitoring vital signs, dressing wounds, and teaching family caregivers how to use complicated equipment at home.
- *Therapists*—who work with patients to restore or maintain their motor, speech and cognitive skills.
- *Homecare aides*—who provide personal services such as bathing, dressing, toileting, making meals, light cleaning, and transporting patients to the doctor.
- *Companion/homemakers*—who help with chores around the house but usually do not perform personal duties for the care recipient.

### Questions to Ask Any Agency You Are Thinking of Working With

- Is the agency certified for participation in Medicare and Medicaid programs (where applicable)?
- How long has the agency been serving the community?
- Is the agency accredited by the Joint Commission On Accreditation of Healthcare Organizations (JCAHO) or Community Health Accreditation Program (CHAP) or other recognized accrediting body?

- Does the agency provide an initial assessment to determine if the patient would be appropriate for home care and what those services might be?
- Does the agency provide all of the services you need? Can they provide flexibility to meet the patient's changing health care needs?
- How does the agency choose and train their employees? Are background checks made?
- Does it protect its caregivers with written personnel policies, benefit packages and malpractice insurance?
- Does the agency provide literature explaining its services, eligibility requirements, fees and funding?
- Does the agency have arrangements in place for emergencies? Are the agency's caregivers available 24 hours a day, seven days a week? How quickly can they start service?
- Are references from former clients and doctors available?
- What types of programs does the company have in place to assure quality care is provided?
- Will the agency go to bat for you if your insurance company or Medicare fail to cover a claim you and the agency thought should be covered?

More information about finding home health care you will be comfortable with is available through NFCA: <http://www.nfcacares.org/pdfs/Health-crPrimer.pdf>

## *Caregiver's Diary*

# Loved one's Health Information

Name:	
Address:	
Date of Birth:	
Phone:	
<b>Emergency Contact(s) additional to caregiver:</b>	
Name:	
Address:	
Phone:	
<b>Healthcare Proxy (if other than caregiver):</b>	
Name:	
Address:	
Phone:	
<b>Health Insurer/Policy #:</b>	
<b>Primary Care Physician:</b>	
Name:	
Address:	
Phone:	
<b>Specialist 1:</b>	
Name:	
Type:	
Address:	
Phone:	

<b>Specialist 2:</b>	
Name:	
Type:	
Address:	
Phone:	
<b>Specialist 3:</b>	
Name:	
Type:	
Address:	
Phone:	
<b>Home Care Aide:</b>	
Name:	
Address:	
Phone:	
<b>Physical Therapist:</b>	
Name:	
Address:	
Phone:	
<b>Other caregiver</b>	
Name:	
Address:	
Phone:	
<b>Allergies:</b>	
Food/Drug	Symptoms:

# Medication Tracking

Because different doctors and specialists may prescribe medications, it's important to have a list of all of them in one place so you can consult the doctor or pharmacist when necessary. Write in pencil so you can make changes when needed.

Name of pharmacy:	
Location:	
Phone:	
Prescription insurance or other ID #	

Name of Medicine/Generic Name		
Date Started		
Form	pill <input type="checkbox"/>	liquid <input type="checkbox"/>
Purpose		
How Much		
How Often		
Side Effects?		

Name of Medicine/Generic Name		
Date Started		
Form	pill <input type="checkbox"/>	liquid <input type="checkbox"/>
Purpose		
How Much		
How Often		
Side Effects?		

Name of Medicine/Generic Name		
Date Started		
Form	pill <input type="checkbox"/>	liquid <input type="checkbox"/>
Purpose		
How Much		
How Often		
Side Effects?		

Name of Medicine/Generic Name		
Date Started		
Form	pill <input type="checkbox"/>	liquid <input type="checkbox"/>
Purpose		
How Much		
How Often		
Side Effects?		

Name of Medicine/Generic Name		
Date Started		
Form	pill <input type="checkbox"/>	liquid <input type="checkbox"/>
Purpose		
How Much		
How Often		
Side Effects?		







# Caregiver's Resources

## Legal Documents

Not everyone will use the same legal documents, so it's helpful to note which your loved one has and where. It's also good to know who has been named in documents such as Powers of Attorney and Health Care Proxies.

Checklist of documents	Where located	Person named
Durable Powers of Attorney		
Advance Health Care Directive		
Directive to Physicians		
Living Will		
Long-Term Care Insurance		
Health Care Proxy		
Revocable Living Trusts		
Designation of a representative payee		
Conservatorship (or Guardianship) of the Estate and of the Person		

## **National Alliance for Caregiving**

National Alliance for Caregiving:

<http://www.caregiving.org/>

National Alliance for Caregiving Family Care Resource Connection <http://web.raffa.com/nac/axa/>

### **301-718-8444**

The National Alliance for Caregiving is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.

## **Family Caregiver Alliance:**

[www.caregiver.org](http://www.caregiver.org)

Family Caregiving 101:

<http://www.familycaregiving101.org/>

### **800-445.8106**

A public voice for caregivers, FCA provides information, education, services, research and advocacy to support and sustain the important work of families nationwide caring for loved ones with chronic, disabling health conditions.

## **National Family Caregivers Association:**

<http://www.nfcacares.org/>

National Family Caregivers Assn. Community:

[http://www.nfcacares.org/join\\_nfca/ind\\_mem.cfm](http://www.nfcacares.org/join_nfca/ind_mem.cfm)

### **800-896-3650**

The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

## **AARP**

[www.aarp.org](http://www.aarp.org)

### **888-OUR-AARP**

AARP is a nonprofit membership organization of persons 50 and older dedicated to addressing their needs and interests.

## **ARCH National Respite Network**

[www.archrespite.org](http://www.archrespite.org)

### **919-490-5577**

The ARCH National Respite Network includes the National Respite Locator Service, a service to help caregivers and professionals locate respite services in their community, and the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels.

## **Administration on Aging (US Department of Health & Human Services)**

[www.aoa.gov](http://www.aoa.gov)

### **202-619-0724**

The AoA provides home and community-based services to millions of older persons, including home-delivered meals programs or nutrition services in congregate settings; transportation; adult day care; legal assistance and health promotion programs.

## **Alzheimer's Association**

[www.alz.org](http://www.alz.org)

### **800-272-3900**

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

## **American Association of Homes and Services for the Aging (AAHSA)**

[www.aahsa.org](http://www.aahsa.org)

### **202-783-2242**

American Association of Homes and Services for the Aging (AAHSA) are committed to providing a full continuum of housing, care and services for older adults. The future of aging services means providing services people need, when they need them, in the place they call home.

### **American Bar Association (ABA) Commission on Law and Aging**

[www.abanet.org/aging](http://www.abanet.org/aging)

**800-285-2221**

The mission of the ABA Commission on Law and Aging is to strengthen and secure the legal rights, dignity, autonomy, quality of life, and quality of care of elders. It carries out this mission through research, policy development, technical assistance, advocacy, education, and training.

### **Assisted Living Federation of America (ALFA)**

[www.alfa.org](http://www.alfa.org)

**703-894-1805**

The Assisted Living Federation of America (ALFA) is the largest national association exclusively dedicated to professionally operated assisted living communities for seniors.

### **Benefits Check-Up and Benefits Check-Up RX**

[www.benefitscheckup.org](http://www.benefitscheckup.org)

**202-479-1200**

A service of the National Council on the Aging, Benefits Check-Up and Benefits Check-Up RX help people over the age of 55 find federal, state, and local public and private programs that may pay for some of their medical care and/or prescription costs.

### **CareCentral**

<http://www.carecentral.com>

**703-302-1040**

CareCentral is a personalized web service that allows users to create a private, secure online community for loved ones during significant health events. It is a free tool to update friends and family, organize and schedule offers to help, and encourage messages of hope, providing support when it is most needed.

### **CarePages**

<http://www.carepages.com>

**888-852-5521**

CarePages are free, private web pages that make it easy to reach out and receive messages of support and to stay connected to family, friends, co-workers and others who care about you and your loved one. The service is available to anyone caring for a loved one, but may be particularly helpful to those who have recently found themselves in a care giving role.

### **Centers for Medicare and Medicaid Services**

[www.cms.hhs.gov](http://www.cms.hhs.gov)

**877-267-2323**

Centers for Medicare and Medicaid Services is the federal agency responsible for administering the Medicare, Medicaid, SCHIP (State Children's Health Insurance), HIPAA (Health Insurance Portability and Accountability Act), CLIA (Clinical Laboratory Improvement Amendments), and several other health-related programs.

### **Children of Aging Parents**

[www.caps4caregivers.org](http://www.caps4caregivers.org)

**800-227-7294**

Children of Aging Parents is a nonprofit, charitable organization that provides reliable information, referrals and support.

### **Eldercare Locator**

<http://www.eldercare.gov>

**800-677-1116**

Eldercare Locator provides referrals to Area Agencies on Aging via zip code locations. Family caregivers can also find information about many eldercare issues and services available in local communities.

**Family Caregiver Alliance:**

[www.caregiver.org](http://www.caregiver.org)

**Family Caregiving 101:**

<http://www.familycaregiving101.org/>

**800-445-8106**

A public voice for caregivers, FCA provides information, education, services, research and advocacy to support and sustain the important work of families nationwide caring for loved ones with chronic, disabling health conditions.

(See the FCA Fact Sheet End-of-Life Decision Making at [www.caregiver.org](http://www.caregiver.org), under “Fact Sheets and Publications”.)

**HealthInsurance.com**

[www.healthinsurance.com](http://www.healthinsurance.com)

**800-942-9019**

This fairly new Web site provides consumers and small businesses with quotes for health insurance, and may help those who have lost their health insurance find an affordable alternative.

**Hill-Burton Free and Reduced Cost Health Care Program**

[www.hrsa.gov/hillburton/default.htm](http://www.hrsa.gov/hillburton/default.htm)

**800-638-0742**

A resource to help those who are unable to pay for care from a hospital, nursing home or other health facility find one of the roughly 200 such facilities obligated under a 1946 law to provide free or reduced-cost care to people residing in their area.

**Hospice Foundation of America**

[www.hospicefoundation.org](http://www.hospicefoundation.org)

**800-854-3402**

Helps those who cope personally or professionally with terminal illness, death and the process of grief and bereavement.

**Lotsa Helping Hands**

<http://www.nfca.lotsahelpinghands.com>

**800-896-3650**

Lotsa Helping Hands is a free-of-charge online service for creating private caregiving coordination communities where family and friends can stay informed and more easily provide assistance and support to caregivers. The service features many communication and social networking tools, including the ability to easily store and retrieve vital medical, financial and contact information, convey medical updates, and post photos. In addition, the easy-to-use calendar is specifically designed for organizing helpers, where everyone can pitch in with meal deliveries, rides, visits, and other tasks.

**Medicare Rights Center**

[www.medicarerights.org](http://www.medicarerights.org)

**888-HMO-9050**

The Center provides hotlines for direct services, education/training, policy briefs, and a list of discount drug programs. The Web site also has a list of phone numbers for each state’s “State Health Insurance Assistance Program and information on the new Medicare law Prescription Drug Cards.”

**Medicine Program**

[www.themedicineprogram.com](http://www.themedicineprogram.com)

**573-996-7300**

This program is for persons who do not have coverage either through insurance or government subsidies for outpatient prescription drugs, and who cannot afford to purchase medications at retail prices.

**NFCA Senior Housing Locator**

<http://www.snapforseniors.com>

**206-575-0728**

NFCA Senior Housing Locator powered by SNAPforSeniors™ is a current, comprehensive and objective resource of all licensed senior housing in the U.S., including assisted living, residential care, nursing care and rehabilitation communities as well as Continuing Care Retirement Communities (CCRC) and a growing number of independent living retirement communities.

**National Adult Day Services Association, Inc.**

[www.nadsa.org](http://www.nadsa.org)

**800-558-5301**

Professional trade association serving adult day center providers, state associations of providers, corporations, educators, students, retired workers and others associated with adult day programs.

**National Association of Area Agencies on Aging**

[www.n4a.org](http://www.n4a.org)

**(202) 872-0888**

Provides information on local Area Agencies on Aging which coordinate a variety of community-based services for senior citizens, including legal services.

**National Association of Professional Geriatric Care Managers**

[www.caremanager.org](http://www.caremanager.org)

**520-881-8008**

Professional association of professional geriatric care managers trained in any number of fields such as nursing, gerontology, social work, or psychology, with a specialized focus on issues related to aging and elder care.

**The National Council on the Aging (Headquarters)**

[www.ncoa.org](http://www.ncoa.org)

**202-479-1200**

National Council on Aging (NCOA) is a nonprofit organization with a national network of more than 14,000 organizations and leaders. Members include senior centers, area agencies on aging, adult day service centers, faith-based service organizations, senior housing facilities, employment services, consumer groups, and leaders from academia, business, and labor.

**National Academy of Elder Law Attorneys**

[www.naela.com](http://www.naela.com)

**(520) 881-4005**

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

**National Foundation for Credit Counseling**

<http://www.nfcc.org/>

**1-800-388-2227**

NFCC can help you locate the nearest nationally certified debt management counselor to you. They can help you in a number of ways, including with negotiating with creditors and creating a budget.

**National Hospice & Palliative Care Organization (NHPCO)**

[www.nhpc.org](http://www.nhpc.org)

**800-658-8898**

NHPCO is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families.

**National Institute on Aging Information Center**

[www.nia.nih.gov](http://www.nia.nih.gov)

**800-222-2225**

NIA provides leadership in aging research, training, health information dissemination, and other programs relevant to aging and older people. NIA is also the primary Federal agency on Alzheimer's disease research.

**National Respite Locator Service**

[www.respitelocator.org](http://www.respitelocator.org)

**919-490-5577**

National Respite Locator Service helps parents, caregivers, and professionals find respite services in their state and local area to match their specific needs.

**National Senior Citizens Law Center**

[www.NSCLC.org](http://www.NSCLC.org)

**(202) 289-6976**

NSCLC closely monitors court rulings, legislation and regulatory changes which affect older persons. They also publish a weekly newsletter.

### **Next Step in Care**

[www.nextstepincare.org](http://www.nextstepincare.org)

Next Step in Care provides information and advice to help family caregivers and health care providers plan safe and smooth transitions for patients.

### **Patient Advocate Foundation**

[www.patientadvocate.org](http://www.patientadvocate.org)

**800-532-5274**

The Patient Advocate Foundation serves as a liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relating to a patient's condition.

### **Partnership for Prescription Assistance**

[www.helpingpatients.org](http://www.helpingpatients.org)

**888-477-2669**

This is the site of the Pharmaceutical Manufacturers Association and has all the information related to the companies' discount and free programs.

### **RxCompare**

<http://www.maprx.info>

**800-MEDICARE**

RxCompare™ is a free tool developed by Medicare Access for Patients-Rx (MAPRx) to help users determine if they need to enroll in a Medicare drug plan and, if they do, to systematically compare the drug plans where they live and select the best option for their prescription needs. RxCompare™ works in tandem with Medicare's on-line "Prescription Drug Plan Finder" and with information available from plans or 1-800-MEDICARE.

### **Together Rx Access**

<http://www.togetherrxaccess.com>

**800-444-4106**

A FREE prescription-savings card for eligible residents of the United States and Puerto Rico who have no prescription drug coverage.

### **Social Security Administration**

[www.ssa.gov](http://www.ssa.gov)

**800-772-1213**

The Social Security Administration's mission is to advance the economic security of the nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security programs.

### **"The Surgeon General's Rx for Caregivers," a downloadable PDF**

<http://www.strengthforcaring.com/util/press/info/Prescription-for-Caregivers.pdf>

### **United States Department of Veterans Affairs (VA)**

<http://www.va.gov/>

**1-800-827-1000**

The VA's goal is to provide excellence in patient care, veterans' benefits and customer satisfaction. Of the 25 million veterans currently alive, nearly three of every four served during a war or an official period of hostility. About a quarter of the nation's population -- Approximately 70 million people -- are potentially eligible for VA benefits and services because they are veterans, family members or survivors of veterans. If you think you may qualify, contact the VA to see if there are any services that may be of help to you.

# *Glossary*

**Advance Health Care Directive.** An Advance Health Care Directive is a document in which you can: 1) instruct your physician as to the kinds of medical treatment you might want or not want in the future (in many states, this is called a Living Will); and 2) choose someone to make medical decisions for you in the event you are unable to make those decisions yourself (in many states, this is called a Durable Power of Attorney for Health Care, or just a Power of Attorney for Health Care). For additional information on advance directives, see the FCA Fact Sheet, End-of-Life Decision Making at [www.caregiver.org](http://www.caregiver.org).

**Attorney-in-Fact.** The person named in a Durable Power of Attorney to act as an agent. This person need not be an attorney.

**Beneficiary.** An individual who receives the benefit of a transaction, for example, a beneficiary of a life insurance policy, a beneficiary of a trust, beneficiary under a Will.

**Conservatee or Ward.** The incapacitated person for whom a conservatorship or guardianship has been established.

**Conservator or Guardian.** An individual who is appointed by the court to act on behalf of an incapacitated person.

**Conservatorship or Guardianship.** A court proceeding in which the court supervises the management of an incapacitated person's affairs and/or personal care.

**Directive to Physicians.** A written document in which an individual states his or her desire to have life-sustaining procedures withheld or withdrawn under certain circumstances. This document must meet certain requirements under the law to be valid.

**Durable Power of Attorney for Health Care.** A type of Advance Health Care Directive, this is a docu-

ment in which an individual nominates a person as his or her agent to make health care decisions for him or her if he or she is not able to give medical consent. This document can give the agent the power to withdraw or continue life-sustaining procedures.

**Durable Power of Attorney for Asset Management.** A document in which an individual (the "principal") nominates a person as his or her agent (attorney-in-fact) to conduct financial transactions on his or her behalf. This document can be either "springing," which means that it is effective only upon the principal's incapacity, or "fixed," which means that the document becomes effective when it is signed.

**Executor.** The individual named in a Will who is responsible for administering an estate during probate. The Executor is the person responsible for making sure all taxes and other expenses are paid and distributing the property of the deceased person in accordance with the Will.

**Federal Estate Taxes.** A tax is due at death if the estate exceeds \$1,500,000 (as of 2004), and is calculated on the value of the deceased person's estate at the time of death.

**Health Insurance Portability and Accountability Act of 1996 (aka HIPAA).** Federal legislation which limits the informal communication of information from doctors and other health care providers.

**In-Home Supportive Services (IHSS).** A program in California that pays for non-medical services for persons who meet certain financial criteria and who could not remain safely at home without such services.

**Irrevocable Trust.** A trust that has terms and provisions which cannot be changed.

**Joint Tenancy.** A form of property ownership by two or more persons designated as "joint tenants."

When a joint tenant dies, his or her interest in the property automatically passes to the surviving joint tenant and is not controlled by the Will of the deceased joint tenant and is not subject to probate.

**Life Estate.** An interest in property that lasts for the life of the person retaining the life estate. When a person who has a life estate interest dies, the property passes to the person holding the remainder interest, without the need for probate.

**Living Will.** A written document in which an individual conveys his or her desire to die a natural death and not be kept alive by artificial means. Unlike a Durable Power of Attorney for Health Care, the wishes in this document are not legally enforceable in California.

**Long-Term Care Insurance.** Private insurance which, depending on the terms of the policy, can pay for home care, or care in an assisted living facility or skilled nursing facility.

**Medicaid.** A state and federally financed program that provides medical care to low income persons. In California it's called Medi-Cal.

**Medicare.** A federal medical coverage program for persons who are over 65 years old or who are disabled. It is funded by Social Security deductions and has no income or resource restrictions. It does not pay for long-term custodial care.

**Probate.** The court proceeding which oversees the administration of a deceased person's estate. Wills are subject to probate; living trusts (if properly funded) are not.

**Revocable Living Trust.** A device that describes certain property, names a trustee (who manages the property) and names a beneficiary who receives benefit from the trust. A living trust is an effective means of avoiding probate and providing for management of assets. It can be revoked by the

person who created it during that person's lifetime.

**Social Security Retirement Benefits.** Benefits, which eligible workers and their families receive when the worker retires. The worker must work for a specified period at a job that is covered by Social Security in order to be eligible for benefits. A worker must be at least 62 years old to receive retirement benefits.

**Social Security Disability Benefits.** Social Security benefits payable to disabled workers and their families.

**Special Needs Trust.** A specially drafted trust that provides a fund to supplement the governmental benefits of a beneficiary while not affecting that beneficiary's eligibility for public benefits.

**Supplemental Security Income (SSI).** A federal program which provides cash assistance to the aged, blind and disabled who have limited income and resources.

**Testator.** The person who executes a Will.

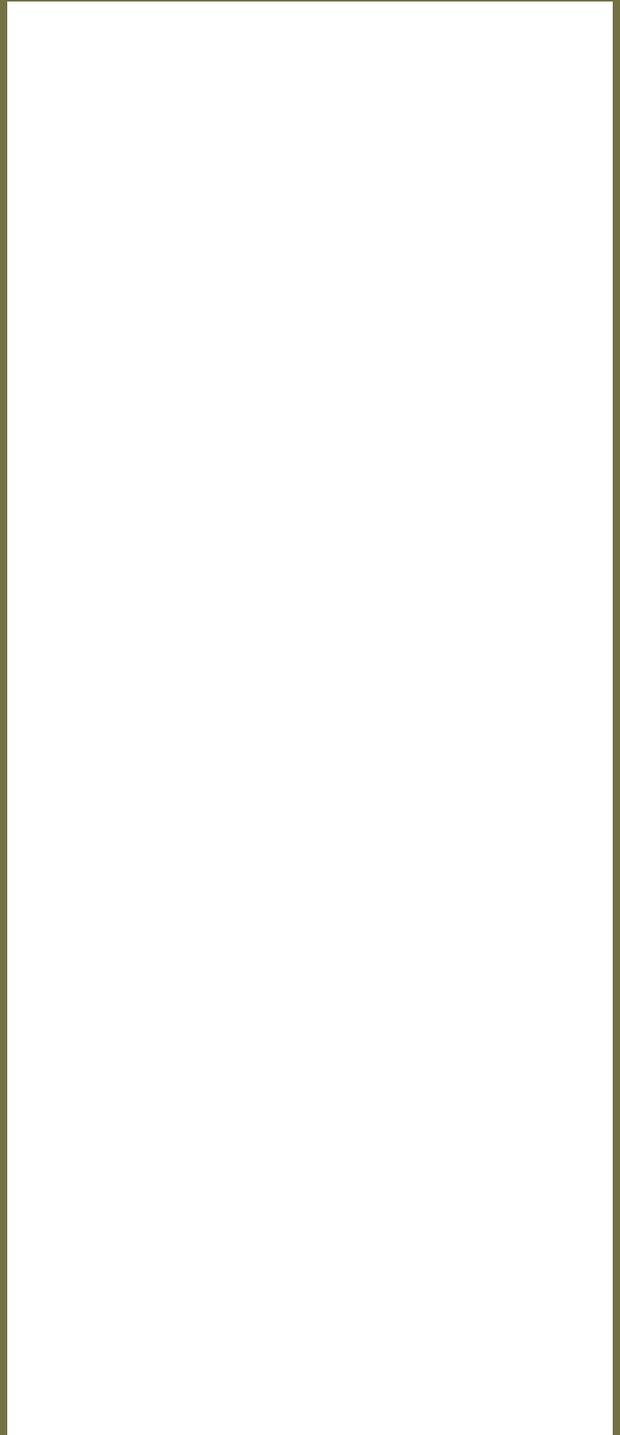
**Trustor (Settlor).** A person who creates a trust.

**Trustee.** The individual who is responsible for managing the property in the trust for the benefit of the beneficiary.

**Will.** The document a person signs which tells how he or she wants his or her estate administered and distributed upon death. It must conform to certain legal requirements in order to be valid. The terms of a Will become operational only upon the testator's death.



# Notes



[www.pbs.org/secondopinion](http://www.pbs.org/secondopinion)

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<http://www.langeloth.org/>

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