

The Caregiver's Home Companion

"Helping Those Who Help Others"

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Special Points of Interest:

- Choosing the "right" care provider for your parents is critical. (P2)
- It is essential to keep up your parents' property, but be mindful of the costs. (P3)
- Keeping your funds separate from those of your loved ones will save you both money on your taxes.(P4)

We're Here for You, That's Our Pledge

Giving care to an adult parent or other family member is by its very nature a series of events, some happy and some frustrating.

Every day and in many different ways, some large and some small, the family caregiver is required to choose amongst often unfamiliar options. The stakes are high; almost all of these choices involve alternatives that affect both the parent and the child. Inevitably, the caregiver becomes the primary decision maker, reversing the parent-child role. It is also an extremely lonely process.

It is this process of assuming control and responsibility that becomes the most burdensome and creates the most doubt and uncertainty.

Many choices are made or heavily influenced by others --- family, health-care professionals, government operatives and religious practitioners. Ultimately, however, the choices become the primary responsibility of the caregiver.

The results are often painful for both the parent and the child. Inevitably, this process results in a continuing series of events that brings the caregiver into conflict with his or her primary role.

The editorial mission of *The Caregiver's Home Companion* is to help its readers better understand and handle this process. Through the experiences of other caregivers, dialogue with professionals versed in these areas and continued emphasis on common-sense solutions, *The Caregiver's Home Companion* is the number one source

for dealing with the pain and joy of being a caregiver.

Each month, we present you with straightforward, tightly written actionable information to help you with your caregiver duties. We include contact information for resources quoted or mentioned in each article of each edition so you may easily follow up on points of interest.

You find a helpful "How I Cope" feature in each issue, a first-person account written by a caregiver like yourself outlining tips they have learned along the way. There also is a Question-and-Answer section for readers to ask the advice of caregiving professionals who will respond to your questions in *The Caregiver's Home Companion*.

Each monthly newsletter can be three-hole punched so you can save every issue in a binder for reference later. Between issues, we send The Caregiver's Hotline, a biweekly update of news relevant to you and the one you care for, delivered online into your e-mail box. From time to time, we include coupons and special offers on items useful in performing your duties, offers that are exclusive to you, the valued reader of *The Caregiver's Home Companion*.

We strive to provide you the most important and useful information and advice we can. But this also is a forum for you, our reader. We welcome your observations, thoughts, questions and suggestions. Contact us at any time at: editor@southportpublishing.com.

We're on the Web at: www.caregivershome.com

Four Key Steps to Selecting A Healthcare Provider

Every day, thousands of new professional homecare providers start work in America. Many are the first outside care providers experienced by a caregiver and their loved one.

Making the right decision on who to bring into the house is crucial. The process of hiring and properly utilizing an in-home aide involves a four-step procedure.

Initially, most family caregivers are reluctant to accept the financial and emotional burden of having a stranger in the house. Then, too, there is the suggestion associated with hiring an outsider that a caregiver is not able to provide all the care by himself or herself.

According to healthcare practitioners, many family members, especially children, view this process as an admission of failure. "They really should view a home health aide as a tool to better care for their parent," said one nurse. "It also provides another set of professional hands to make their parent more comfortable."

Unfortunately, as these healthcare practitioners and others often find, the first-time home care provider is not only helping the elderly patient but also educating the family caregiver.

"This is the second step in the process," one said. "We're here to help but it needs to be viewed as a team effort. Building that trust is always a slow process and it begins in the interview stage," she added.

The third step in the process is to identify what the homecare provider will do and what the caregiver retains for himself or herself.

Rondella White, a homecare provider for 25 years, talks about the daughter of one elderly parent who would not permit her to wash the patient. "This put a burden on all of three of us," Ms. White said, "and prevented us from giving the woman the best care. Finally, I told the daughter to let me do the washing and she could comb her mother's hair. It worked, and everyone was happier."

The fourth step is gaining the trust of the elderly patient. Often, they view the home health aide as a stranger and intruder. This feeling is particularly true when the aide is in the house alone with the parent.

Ms. White suggests that the family caregiver be present the first week a new home aide is in the house. "Just having the son or daughter in the house is reassurance," she says. "I always try to make noise before appearing in a room with the parent. I also try to talk with the parent as I enter or leave the room. It's always a good way of keeping them involved with you and to help them make the adjustment."

Ms. White and other caregivers contacted emphasize that they are not substitutes for the caregiving child. "We're there to help and to ease the strain of caregiving. We're not replacements. This is a fear that many parents have — that the children will go off and leave them," Ms. White said. "Of course, I have seen that happen, but usually in the long run there is nothing but unhappiness."

Summing up the four key steps in getting a home aide:

- Recognition that another set of hands is needed.
- Delineate responsibilities.
- Help the parent accept a stranger in the house.
- Reassure the parent that the children are not abandoning them.

Resources

- National Association for Home Care - www.nahc.org
- National Hospice & Palliative Care Organization (NHPCO) - www.nhpc.org
- Visiting Nurse Associations of America - www.vnaa.org
- American Nursing Association - www.nursingworld.org

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Nine Tips for Choosing the Right Healthcare Provider

Here are Nine Tips for Choosing the Right Home Care Provider for You:

1. Make sure he or she comes from an agency or is well referenced.
2. Always ask why he or she is a home health aide and why they are looking for a new position.
3. Try to determine how helpful the applicant will be on the job. One family care giving veteran drops her purse during the interview and sees if the applicant attempts to retrieve it for her. If the person doesn't do this, they will not be very helpful on the job.
4. Ask the applicant if they have a way of handling bedridden patients. There are many tricks to this process and the good home health aides have many well thought out approaches.
5. Check for personal hygiene. Clean fingernails are an absolute requirement and should be checked discreetly during the interview.
6. Try to determine the family background of the applicant. Home aides with siblings and who have cared for ailing family members have proven to be the best providers, according to many experienced family caregivers.
7. Provide an incentive program. Ask the applicant if they would agree to a trial period with a bonus if they prove effective. This is another positive test that has been used effectively by caregivers.
8. Drive past the residence of any potential home aide. How they keep their home and family will be a good indication of how they will provide home care.
9. Maintain a discreet emotional distance from any home aide. Remember, the aide is an employee and works for you and your loved one. Most caregivers are hiring their first domestic help in this situation. Maintaining a distance will enable you to better monitor the care of your parent.

What to Do When Your Parent's House is Falling Down

The natural thing to do when something goes wrong in your parent's house is to fix it. But this may be the wrong thing to do if you want to maintain separate households for tax and purposes of medicare eligibility.

It is a sad fact today that most families can't afford the financial impact of long-term illness. With the elderly



It's important to show who paid for the repair.

living longer and medical expenses increasing at rates far in excess of inflation, medical bills can bankrupt a great many families without federally sponsored help.

A recent government report indicated that healthcare costs had increased 35% since 1997 while overall inflation had gone up only 2.3%.

(Continued on P4)

Timely Tip:
For the purposes of establishing Medicaid eligibility, it is important to keep a caregiver's household income and expenses separate from the parent's assets.

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Think Before Repairing Your Parent's Home

(Continued from P3)

For purposes of establishing Medicaid eligibility, it is important to keep a caregiver's household income and expenses separate from the parent's assets. This is particularly true if they own their home.

If something does go wrong at your parent's home, it is important to have it fixed. It is equally important that, whenever possible, the cost of that repair be provided through an account at least partially held by the person cared for.

Demonstrating their independence will help you help them in the future.

When possible, a caregiver should pay for the repair with the parent's checking account or with a money order. This will enable you to demonstrate to any state or federal agency that you are not responsible for their household.

From a tax standpoint, if repairs are done by a caregiver or other family member, careful records should be kept of what was done, the cost of materials, time spent and an estimate of in-kind value provided in some written documented form.

Timely Tip:

Look into "Golden Age" bank accounts for your senior loved one and use it to keep expenses separate for tax purposes.

Five Ways to Keep Funds Separate

Banks across the nation offer senior citizen accounts. A child or sibling providing caregiving support should make sure each parent or sibling has a separate account. Because most "Golden Age" accounts are free, having separate accounts is not an onerous expense.

This will ensure a steady, dependable and legal means of demonstrating the independence of your parent's household.

There are tax and other financial benefits for this activity. Among these is proof that the caregiver did not benefit beyond the legal limits and therefore need not report added income on their own returns.

The IRS reported in 2000 that more than 35,000 caregivers needed to revise their tax returns due to faulty bookkeeping. According to the IRS, most did not need to pay additional taxes but were faced with audits for current and prior years. As everyone knows, audits are not easy to prepare for or to undergo.

If a parent or sibling is receiving government checks, it is important to demonstrate a clear paper trail demonstrating that the

money was received and endorsed by the addressed recipient. If there are two parents, it is best to have two separate accounts and deposit the appropriate checks in these accounts for disbursement.

If there is a horde of savings, stocks, or other financial instruments, caregivers should keep detailed records of:

- When these assets were liquidated
- Why the money was dispensed
- Documentation on how assets benefited the parent or sibling
- Proof that the caregiver did not benefit
- If gifts to children or others were included, demonstrate they were within the non-taxable guidelines established by the IRS.

Note also that certain state tax regulations may vary, and you should consult an accountant for the rules in your specific circumstance.

We're on the Web at: www.caregivershome.com

New Government Rules Protect Your Loved One's Privacy — Even From You

In April, new government regulations went into effect that will make it more difficult for you to obtain information about your loved ones. Under a 1996 federal law, healthcare providers are being asked to be more careful in disclosing information about patients. The law was originally intended to help people protect their medical rights when moving from job to job.

The new rules have driven doctors to eliminate sign-up sheets in offices, dentists from putting charts with patient names on desks and hospitals withholding names of accident victims from news organizations.

At a recent gathering of general parishioners and physicians concerned with providing healthcare for elderly patients, many doctors expressed bafflement about the new rules as regards relatives or unlicensed caregivers. The informal consensus reached at this meeting was that physicians needed to be careful as to what they shared. Many said they would continue to provide information but only on a more restricted "need to know basis." Others said they were looking for new guidelines from their institutions. All agreed that the rules would "dampen" their communications with caregivers.

"How do I know sharing information on a parent with one child doesn't offend or anger another who is disputing care or inheritance," one doctor said. "I can just

see someone suing under these new regulations."

For some doctors, a written authorization doesn't seem to be enough. Nonetheless, for caregivers, the new rules seem to mean they need to insure that physicians, doctors and dentists have written authorization to share information.

For caregivers, the new rules appear to mean they will need to insure that physicians, doctors and dentists have WRITTEN authorization to provide information to them about their parents or other charges. (A sample form is shown below.)

Also, the new regulations have forced hospitals to build walls around admission desks and block off patient charts from the view of visitors. Gone, too, is the traditional patient chart at the foot of the hospital bed.

For patients in states that do not require healthcare facilities to provide patient information, the new rules will make it easier to obtain this data. However, many providers are charging for this service, often running into the hundreds of dollars for prolonged illnesses.

In general, the rules say, healthcare providers must limit the disclosure of personal health information to the "minimum
(Continued on P7)

Timely Tip:

Always keep a list of your loved one's medicines and the name and number of your family physician with you. It will help other healthcare professionals provide better care.

To whom it may concern:

I, _____ hereby authorize all my healthcare providers to share information concerning my condition in any detail so desired, to my

_____, _____ in order to help him/her make
(Relationship) (Name spelled out)

informed decisions about my care and well being. This document was signed in the presence of one witness whose name and signature are affixed below and in the presence of

_____, who is providing care for me.

Signed: _____

Date: _____

Full Name _____

Witness: _____

Full Name _____

Thank you for your help in this matter.

The Caregiver's Responsibility Your Loved Ones Have a Mind of Their Own

The caregiver in many situations is often ill-prepared to deal with the changing relationship unfolding before them. However, it is up to the primary caregiver to deal with these situations and to maintain focus on what he or she wants to do and can do.

This is the key point to remember:

Parents can't be changed, they can only be dealt with.

When a child becomes a caregiver, the parent-child roles gradually reverse. This is inevitable, say healthcare professionals. In many cases, as parents are losing capabilities to be independent, they begin to resent the efforts of their children to do more for them.

"It is an inevitable consequence of deteriorating health," reports Dr. Karen Metzger, a Brooklyn (N.Y.)-based psychologist. "The parent feels as if they are losing control and seeks ways of maintaining some semblance of order and, in their minds, dignity."

Metzger and others point out many parents simply want to continue to do for themselves for as long as they can.

"Any individual values independence," she adds. "The key thing a caregiver should understand is that there can be a balance between giving and allowing the parent (or sibling) to do for themselves. Knowing the balance is key."

Home health aides report that often the most difficult adjustment to be made is with bathing.

"No parent wants to be seen naked and exposed and helpless," said one health aide with 20 years experience. "I find this particularly true of men who are being cared for by daughters. It gets worse for sons and fathers, but there is a little bit more acceptance there."

Other problems arise when it comes to food and cooking.

"A lot of parents resent not being able to cook in their own kitchens," Metzger said. "Also, older people have their own diets and likes. Sometimes, the caregiver tries to give them something they think will be more healthful. This can lead into some strained relationships."

Metzger's advice, "Let them be."

...many parents simply want to continue to do for themselves for as long as they can.

Timely Tip:
As the traditional parent-child roles reverse with caregiving, it is important to remember that you are not likely to change your parent's way of life, but you can find ways to deal with it effectively.

New Drug Slows Alzheimer's Progression

The progression of Alzheimer's disease in patients with moderate to severe cases was slowed by a new drug available in Europe and currently under review by the Food and Drug Administration in the U.S.

The drug, memantine, would be the first drug with a label offering treatment for the most advanced Alzheimer's cases.

It regulates a brain transmitter suspected of playing a role in the disease.

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New Government Rules (Continued from P5)

necessary" to achieve a given purpose. In practice, some providers say, changes include removing patient's names from the outside of folders and putting up partitions separating receptionists from waiting patients so they will not overhear appointments being made.

For caregivers, the new rules, until they are clearly defined, will force them to make extra calls and to provide authori-

zation in order to be fully briefed about their parents' condition.

A suggested course of action: copy the authorization form on page 5 and make sure your loved ones have signed and dated it. Copy the document and provide it to all healthcare providers involved with their care. Also, remember to keep the original with you should an unexpected emergency bring in a new set of providers.

Many Are Unprepared For Caregiving

Americans find themselves in the role of caregiver for a relative or even a friend. But experts worry that most are not prepared psychologically, physically or monetarily to handle the growing demand, according to writer Janet Kornblum in USA Today.

As 3,700 caregivers and others recently gathered in Chicago for the joint Conference of the National Council on Aging and the American Society on Aging, the focus was on the needs of millions of the nation's volunteer caregivers.

National and local organizations have emerged in the past several years to help people deal with problems and issues that arise: balancing work and family with caregiving duties; managing both their own finances and the finances of their loved ones; dealing with their own emotional needs and simply finding help from organizations.

Policy makers and advocates worry now that people who need assistance aren't getting it, often because they don't define the tasks they do (such as shopping, doctor visits) as actual caregiving.

They also worry about a future where the needs of a rapidly aging population could outstrip available programs. Local programs all over the country are facing budget cuts, says Bonnie Lawrence of the Family Caregiver Alliance. And that's happening as the scope of the problem expands. Says Paul Kleyman of the American Society on Aging: "What we're seeing is the groundswell of baby boomers dealing with issues of aging."

Today, nearly one out of every four U.S. households — 22.4 million households — helps to care for someone 50 or older, according to the Family Caregiver Alliance.

Josefina Carbonell, the Department of Health and Human Services' assistant secretary for aging, says the government must change the way the elderly are cared for.

"Seventy-five percent of our public funding for long-term care still goes to nursing-home care," said Carbonell. "We need to reverse this current reality and dramatically expand home- and community-based care."

Timely Tip:

Set yourself apart from the majority of family caregivers by getting yourself as prepared as possible for the duties you've undertaken.

Tough Coach, Tough Love, Tough Talk

St. Louis Rams Coach Mike Martz had some strong words for a Congressional subcommittee on behalf of the Alzheimer's Foundation.

The NFL coach spoke in April at hearings on funding for a disease that afflicts nearly four million Americans.

Martz described how his mother, who was afflicted, would laugh and talk about things like pruning.

"The last time I saw her, we took a walk in the rose garden," Martz said. "She loved gardening. She started to weed things and turned to me and said, 'Now, who did you say you were?'"

Martz and others at the hearing were urging added funding for the Foundation.

"How I Cope"

A Story of Caring for an Estranged Loved One

Although hard to find, help does exist. You do not have to abandon caring for loved ones who abandon you.

By Carol Celeste

When paranoia led my aged father to shut me out of his life and deny his mental slippage, I discovered "the system" only reacts to catastrophe; I wanted to prevent one.

Here are some of the things I did to help my father. This tragedy can befall any family caregiver at any time, and my experience may help you.

Enlist help from friends. I told neighbors, friends, and my dad's favorite waitress about the situation. They provided information about his behavior and needs along with basic care (filling the pill dispenser, driving to appointments and errands, bringing food) at my direction.

Inform doctors immediately. After learning of his advancing dementia, the doctor prescribed medication and got my dad to agree to a psychiatric evaluation. He also updated me on my dad's medical condition and recommended other resources for special needs.

Notify social services. I asked neighbors to call the police for a "welfare check" if safety became an issue. A care consultant with the Alzheimer's Association (national referral:

800-272-3900) recommended repeated calls to Adult Protective Services (sometimes called Older Adult Services or Public Health Services) to establish a record of self-neglect or fiduciary abuse. They send trained professionals to investigate hygiene, self-sufficiency and undue financial influence by others, then take appropriate action, without revealing who called. I found other sources of legal, medical and caregiving aid from my Area Agency on Aging (800-677-1116 for referrals).

Know the relevant law. Conversations with lawyers and an Internet search explained what powers my state and local laws allow family caregivers to assume, and whether legal action

would help or hurt. Elder law specialists are listed by Zip Code at <http://library.lp.find-law.com/eldercare.html>.

A rebellious care recipient poses special challenges, and unfortunately available literature ignores estranged family caregivers. Although hard to find, help does exist. You do not have to abandon caring for loved ones who abandon you.

Award winning writer Carol Celeste is working on a book dealing with caring for estranged loved ones. She can be reached at ccwritercwc@hotmail.com.

Enlist help from friends. I told neighbors, friends, and my dad's favorite waitress about the situation.

Timely Tip:

If your parent is resisting your help for whatever reason, innovatively get others to help by directing care from behind the scenes.

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NEXT MONTH:

A review of Elizabeth Cohen's, *The House on Beartown Road*. It recounts her experiences as a single mother raising a daughter and caregiving an Alzheimer's stricken father.