

Caregiver's

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H E L P I N G T H O S E W H O H E L P O T H E R S

Medicare D's Potholes and Pitfalls

Strategies to Help Your Elderly Make the Right Decision Right Now



By Paula Sanders McCarron

Editor's Note: *Editor's Note: Medicare Part D, the first full-fledged drug coverage program for America's elderly, is launching amidst controversy, complexities and confusion. In this third installment of our series **Boon or Boondoggle—21st Century Medicare**, we look at caregiver strategies for assuring that a loved one's plan decision is timely—and the best for them.*

At first, Medicare Part D seemed to be just what the doctor ordered—a new federal program designed to provide affordable prescription drug coverage for approximately 43 million Medicare beneficiaries. But in the weeks since its roll-out in mid-October, Medicare D has been fraught with controversy, chaos, and in some cases, contempt.

"It's a new program, a complex plan, and the implementation has been imperfect at best," says Judith Stein, executive director of the Center for Medicare Advocacy. The Center, ►

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Medicare Part D *Continued from page 1*

headquartered in Willimantic, Connecticut, is a national non-partisan organization working to increase access to comprehensive Medicare coverage and providing education and advocacy to Medicare beneficiaries.

As the daughter of a Medicare beneficiary, Stein knows firsthand the frustrations facing both Medicare beneficiaries and family caregivers. While attempting to help her mother enroll in the Medicare-approved prescription drug plan, Stein encountered inaccurate information, non-functioning websites, overloaded phone lines, and the difficulty of wading through and comparing plan details and formularies.

"What we're seeing with the implementation of Medicare D is the move of Medicare from a uniform national plan into fragmented, private plans. It's an economic shift as well as a philosophical one," says Stein. "We're moving to a process where it's every beneficiary for him or herself."

Those who favor privatization typically take the stance that, because of competition, privatization will provide more choices for consumers and therefore lower costs. It is true that Medicare D has provided every Medicare beneficiary with a minimum of 11 plans to choose from; however, whether Medicare D will actually help most seniors to limit or reduce their prescription drug costs is yet to be known.

In fact, one study released by Representative Henry Waxman of California reveals that the 10 top selling drugs among seniors actually will cost on average 3% more through Medicare D than if the same drugs were purchased through discount retailers such as Costco or Drugstore.com

Although another huge government agency, the Veteran's Administration, uses its buying power to negotiate lower drug prices, Medicare is prohibited from negotiating with drug manufacturers, plan providers or pharmacies for discounts on bulk prescription purchases.

Additionally, Medicare D may have severe financial consequences for many of the low income seniors and adults with disabilities who are enrolled in both the federal Medicare program and a state-sponsored Medicaid program. Many of these individuals currently receive assistance with obtaining their medically necessary prescription drugs at no or little cost, but these same individuals are required to enroll in Medicare D plan by January 1, 2006, or they will simply be assigned a plan. Once enrolled in a Medicare D plan, many of these "dual eligibles" will become responsible for meeting out-of-pocket expenses related to their prescription drug plans such as monthly premiums, deductibles, non-covered medications and co-pays.

As Governor John E. Baldacci of Maine points out, this change will affect 85,000 people in Maine alone and result in "less drug coverage at a higher cost." In Maine, as in many other states, efforts are now under way to increase education of consumers and provide financial assistance to low income beneficiaries.

Even in the midst of all the confusion and controversy, Stein believes seniors and family caregivers should not give up on Part D. "But given the complexity of the program, there should be some changes made while we're in this first stage of implementation," she says.

Three changes which Stein would like to see instituted include:

1. An extended enrollment period beyond May 15, 2006, to allow individuals more time to become educated and shop for a drug coverage plan best suited to their needs.
2. A removal of the "lock in" which restricts or penalizes individuals who enroll in one plan and then wish to change to another plan.
3. The elimination of penalties for late enrollment.

As of December 2, the White House was opposing an extension of the enrollment period, although a test vote in the Senate showed a majority of Senators were in favor of either extending the enrollment period or dropping the penalties.

While legislative changes could help, most family caregivers are more concerned with helping their loved ones choose a plan before the existing deadline of May 15. To aid you in the selection of a plan, and to survive the yet-to-navigated waters of Medicare D, here are some strategies:

Take the Boy Scout Approach: Be Prepared

Since much of the information on Medicare D and individual drug plans is available online, Stein advises family caregivers to utilize online resources and have a printer ready for information you want to keep. It's impossible to compare plans without having a listing of your loved one's medications, so have that handy as well.

Seek Out Specific and Reliable Information

Look for up-to-date information from trusted sources. Most government websites are now operational, and it should be easier to get through on phone lines. Visit the official Medicare website at www.medicare.gov or phone (800) MEDICARE for information. The Center for Medicare Advocacy can be reached at www.medicareadvocacy.org or (860) 456-7790. Two valuable resources provided by the Center include a state-by-state breakdown of Medicare D plans available in all 50 states as well as information about financial assistance for low income beneficiaries.

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Overcoming an Intimidating Task

7 Tips for Bathing Your Elderly Loved One

By Ursula Furi-Perry

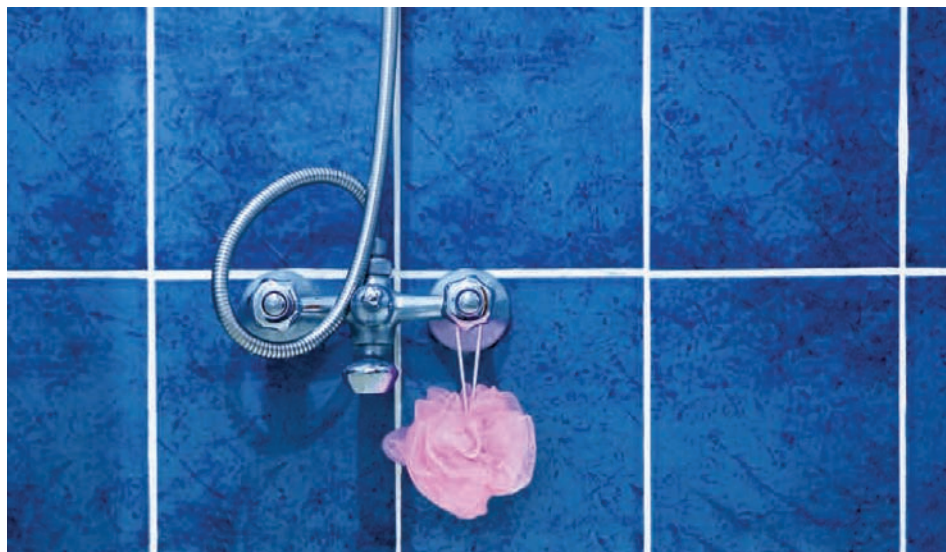
Bathing and grooming your loved one is an essential part of caregiving, but it often becomes a daunting task for caregiver and loved one alike.

"Most of the time, we're caring for someone who has always taken care of us," explains Anne Bannes, long-time caregiver and vice president of community services at St. Andrew's At-Home Service for Seniors in St. Louis, Missouri. "When you're giving a bath, it gives you a more acute view of their frailty, and (highlights) all the more you have to do for them on a physical plain."

Not only can bathing be physically draining, it may also carry some deeply-rooted emotional and psychological implications that other caregiving tasks don't. For instance, the lack of privacy and independence associated with bathing may make both caregiver and loved one uncomfortable, even humiliated. "No one wants their child or grandchild to do these things for them," says Shelley Ludwick, director of clinical programs and education at the Visiting Nurses' Association of America.

Fortunately, there are several things caregivers can do to make bathing and hygiene easier on themselves and their loved ones.

For starters, experts say caregivers should provide as much privacy as they safely can in an effort to minimize feelings of humiliation on both parts. "Promote as much independence as possible," Ludwick says. If your loved one is able to shower by herself, let her—all the while staying at a safe distance to guard against falls or other injuries and assist as needed. "I used to set everything up for my mother in the bathroom and was there at the door just in case," Bannes recalls.



Shower curtains may promote privacy as long as they allow the caregiver to safely monitor the loved one's bath as necessary. "Also, cover all areas of the body not being washed with a towel, so they won't be exposed," Bannes recommends. Simply turning your head away whenever possible, for modesty's sake, may also work wonders.

Whether your loved one is able to bathe independently or needs considerable help, you can safeguard against hazards by installing a variety of adaptive equipment. Shower seats and bath stools may make bathing easier if your loved one can't stand for long periods of time or is shaky on his feet. Non-stick bath mats can help avoid slips and falls. Safety bars in bathtubs and next to toilets can aid with balance, and a wheelchair or other equipment may help caregivers transport a loved one to the bathroom. Adaptive equipment is available at many home improvement stores and even pharmacies.

Those who can't afford safety gear should check with their area senior agencies. "Many of the senior programs in the community also collect these things, which then get recycled in the community," says Ludwick.

Just as important as installing the right safety equipment is getting proper train-

ing, experts say. "(Bathing techniques) can be very easily taught, as can turning and transferring your loved one," says Bannes. "Caregivers should check with their local visiting nurses' associations and home care agencies. Many communities have caregiver training courses, and there are also caregiver books which contain valuable information," Ludwick advises.

To be sure proper bathing techniques are followed, caregivers should understand that each loved one's hygienic needs are different, and come up with a bathing and grooming plan according to their loved one's individual needs. Some loved ones, for instance, may need sponge baths or bed baths, while others are capable of taking showers or tub baths. Many experts will agree that there's no need to bathe loved ones daily unless problems with incontinence arise; Ludwick recommends routine bathing two or three times per week.

When picking out bath products and cosmetics, caregivers should keep in mind their loved ones' skin type and skin sensitivities. "A lot of times, older people have very sensitive skin and fragile skin," says Ludwick. "You want to look for a product that works for them."

Keep in mind any allergies or irrita-

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7 Tips for Bathing your Elderly Loved One

Continued from page 3

tions your loved one may have, which could call for a hypo-allergenic product. Also note that no-rinse products are available to make bathing even easier. Talk with your loved one's doctor for recommendations and schedule a consultation with a dermatologist specializing in geriatric care if needed.

Candid personal conversations and honesty are another essential part of planning your loved one's bathing. If emotional or psychological issues are becoming overwhelming and your loved one absolutely refuses to let you bathe her, "you may need to have some difficult conversations," says Bannes, explaining that "part of good health is hygiene and you need to make sure that they have a thorough bath." Adds Ludwick, "Always be aware of how they're feeling...this can get frustrating because the caregiver is thinking 'I just want to help.'"

Finally, caregivers must recognize that it's perfectly okay to ask for help or even leave bathing to someone else. A home healthcare assistant or visiting nurse can provide professional bathing and grooming services, and other family members and friends in the community may also step in. In fact, the caregiver isn't the only one to get some relief if another person is doing the bathing: often, loved ones might be less reluctant to take a bath if it is assisted by a stranger.

"Check with all of your local Area Agencies on Aging to see if you qualify for their assistance," says Bannes. "Also, check with your visiting nurse association and home care associations to see if there are covered services available," adds Ludwick. ■

RESOURCES:

Visiting Nurse Association of America, online at www.vnaa.org or phone (617) 737-3200.

National Association for Home Care and Hospice, member state associations website, www.nahc.org/Consumer/stassn.html

AoA's Family Caregiver Support Program, state-by-state contacts, www.aoa.dhhs.gov/prof/aoaprogram/caregiver/careprof/state_by_state/state_contact.asp



STRESS-BUSTING

Managing Your Own Mental Health

By Lori Ritchie

The challenges of caregiving are fraught with stress and demands that are often beyond what many people could ever imagine, beyond what some people can handle emotionally and psychologically.

"My role as a caregiver has brought me great mental, physical, and horrible financial problems," says Houston caregiver Nora Jean David. "I have been to the edge and back, and I know exactly what that is. Sometimes I get on the edge even now because no one knows how hard this job is."

Just as David points out, caregiving responsibilities can permeate many aspects of our lives and can push even the most stable individual beyond their limits.

Naturally Negative Feelings

Caregivers may experience a range of feelings throughout the caregiving journey—sadness, fear, frustration, helplessness, anger, resentment, loneliness, fatigue, embarrassment, shame, guilt, and uncertainty, just to name a few. Such feelings are natural and are actually part of

the grieving process. Grief for a loved one who is chronically ill begins long before the relative passes away.

The main thing to realize about all of these feelings is that ignoring them or refusing to acknowledge them will not make them go away. Find a way to express these emotions in a healthy way—with a support group, within the pages of a journal, or with a family physician. Denial and refusal to deal with these feelings can lead to mental health concerns.

Caregivers may find that changing traditional roles with a chronically ill parent is especially challenging. "It can be a difficult transition for a child to take on the role of 'parent' and decision-maker," says Dr. Diana R. Kerwin, assistant professor of medicine in the Division of Geriatrics and Gerontology at Medical College of Wisconsin. "The child often needs to be empowered to step in and

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begin caring for their ailing parent — making sure their parent takes his or her medication, for instance, or telling their parent they should not drive, and making difficult decisions about when the parent is no longer able to safely live alone.”

Stress and Depression

Stress and depression are two of the most common mental health concerns. According to the Alzheimer’s Association, more than 80% of Alzheimer’s caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression.

The Alzheimer’s Association provides these warning signs of caregiver stress:

- Anger
- Anxiety
- Denial
- Depression
- Exhaustion
- Health problems
- Irritability
- Lack of concentration
- Sleeplessness
- Social withdrawal

The Association recommends that caregivers who regularly experience these feelings seek assistance from their family physician.

The National Family Caregiver Alliance estimates that approximately 80% of the long-term care in the United States is provided without compensation. This is a statistic that underscores the financial burden caregivers endure. Many caregivers are responsible for their own children and households as single parents, a high-stress situation in its own right. Financial concerns can definitely increase stress levels and contribute to feelings of depression.

Could the sadness, loneliness or anger you feel today be a warning sign of depression? People experience depression in different ways. Some may feel a general low-level sadness for months, while others suffer a more sudden and intense negative change in their outlook.

Consider these common symptoms of depression. Have you experienced any of the following for longer than two weeks?

- A change in eating habits resulting in unwanted weight gain or loss
- A change in sleep patterns—too much sleep or not enough
- Feeling tired all the time

- A loss of interest in people and/or activities that once brought you pleasure
- Becoming easily agitated or angered
- Feeling that nothing you do is good enough
- Thoughts of death or suicide, or attempting suicide
- Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders and chronic pain.

Making the decision to move a loved one to a care center is very stressful. The responsibilities of monitoring the care a loved one receives in a new location and feelings of guilt and loneliness can carry its own brand of stress. It’s not uncommon for caregivers to feel depressed at the time of placement and even continue to feel depressed for a long time afterwards.

Strategies to Help Yourself

Caregiver Nora Jean David says “prayer and faith in God” are her number one coping tools. “Acceptance has also been important. I fought this thing for years, and I felt cheated out of part of my life because I have no time for me. Now, I just pray and accept this as a way of life.”

David says she also tries to sleep late on Sunday mornings to allow her body and mind to refuel and sees her family

READER RESOURCES

To help keep your own mental health in check, look into the insight these books can provide:

Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive by Claire Berman. Published by Henry Holt and Company, Inc. 115 West 18th Street, New York, NY 10011, (212) 886-9200.

The Caregiver Helpbook: Powerful Tools for Caregiving by Vicki Schmall, Marilyn Cleland and Marilyn Sturdevant. Published by Legacy Health System. Accompanies a class by the same name. Class information and the book are available by contacting Legacy Caregiver Services, 1015 NW 22nd Ave., Ste. N300, Portland, OR 97210, (503) 413-7706.

Caregiving: The Spiritual Journey of Love, Loss, and Renewal by Beth Witrogen McLeod. Published by John Wiley & Sons, Inc., New York, NY.

doctor on a regular basis to keep her own health problems under control.

Here are a few more strategies to help caregivers cope with stress and depression:

- Exercise has been found to reduce the effects of depression. Walking three times a week for 30 to 45 minutes has been linked to reducing or alleviating symptoms of depression.
- Eat a healthy diet rich in fruits, vegetables and whole grains and low in saturated fat. Ask your healthcare provider about taking a multivitamin as well.
- Try to get enough sleep and rest.
- See your healthcare provider for a checkup. Talk to your provider about symptoms of depression or illness that you may experience. Seek counseling, if needed.
- Stay in touch with friends. Social activities can help keep you feeling connected and help with stress. Faith-based groups can offer support and help to caregivers.
- Find a support group for other caregivers in your situation (such as caring for someone with dementia). Many support groups are available online through the Internet.

An excellent resource for caregivers can be found at www.nwrcwa.org/care-giving.pdf. This free support kit covers topics such as a Caregiver’s Bill of Rights, caregiver fatigue timeline, caregiver stress test, and a unique list of ways to cope.

Also, be sure to check out the Caregiver Survival Guide available free on the CaregiversHome website at www.caregivershome.com. The guide is rich with tips on avoiding stress and dealing with the daily caregiving challenges.

Overall, just remember that help is available when you’re feeling that you can’t handle the demands that caregiving has placed upon you. And you are not alone. ■

RESOURCES

National Mental Health Association depression screening checklist at www.depression-screening.org

Family Caregiver Alliance at www.caregiver.org

National Institute of Mental Health at www.nimh.nih.gov

National Mental Health Association at www.nmha.org

Safeguarding Mom and Dad

Who's Preying on Our Parents?

By Kelly Morris

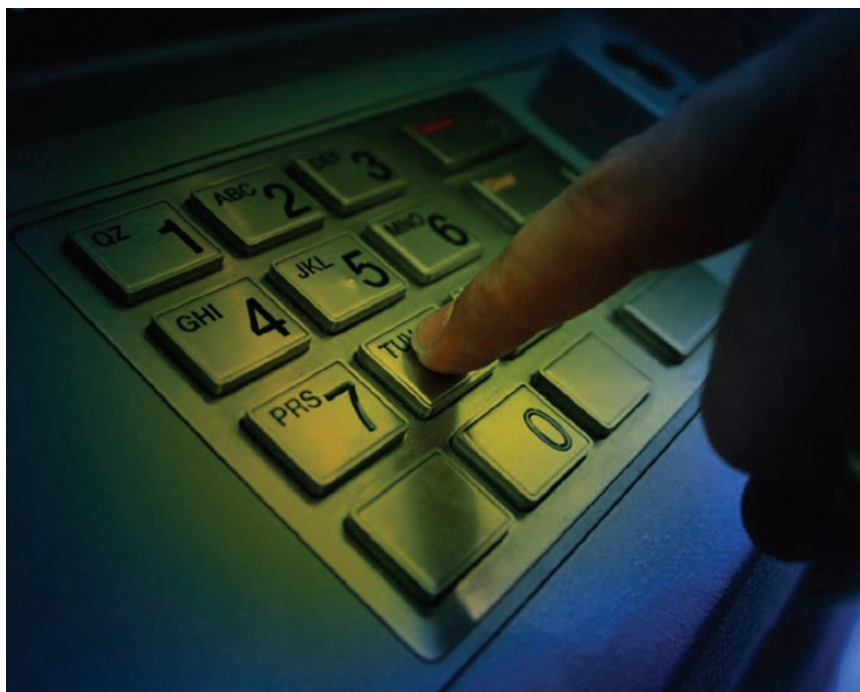
LOTS OF PEOPLE, THAT'S WHO.

Take telemarketers, for example. Sure, there are legitimate telemarketing companies. But the FBI also reports that there are about 14,000 illegal telemarketing operations that prey on unsuspecting people. And our aging parents are a favorite target. In fact, consumers lose as much as \$40 billion every year to fraudulent telemarketers.

And that's not all. AARP reports that elderly people are frequently victimized by all kinds of scams, including:

- "Phishing," when con artists attempt to gather personal information by phone or computer by asking consumers to "update" or "verify" billing information, such as credit card information and Social Security numbers.
- Charity fraud, when con artists solicit donations for phony charities.
- Sweepstakes fraud, when unsuspecting people are told they have won a prize and only need to pay a small fee for "processing" or for delivery.
- Phony health insurance policies, when elderly people are sold health insurance plans by non-existent companies that will never pay.
- Home repair scams, when homeowners are told they need extensive repairs to their homes; once they pay, the repairs are never done.

What makes our elderly parents so vulnerable to this kind of thing? After all, they're not stupid. They are, however,



trusting. They don't expect crooks to be calling them. They want to take people at their word. They don't want to appear rude by hanging up on a caller.

Elderly people are often very concerned about their financial well-being, and this makes them easy targets for con artists offering fraudulent investments or other "get rich quick" schemes. Elderly people also tend to worry about their health and the increasing costs of medical care, and this makes them vulnerable to scams offering phony health insurance.

Finally, the elderly are often embarrassed when they are hooked by such scams and don't want their children to find out. They may fear that their children will think they are no longer competent to care for themselves and may worry about losing their independence.

They rarely report fraud, so scam artists get away with it, explains Diane Terry, the senior director of the Fraud

Victim Assistance Department at TransUnion, one of the top three credit reporting agencies in the United States. In fact, says Les Henderson, Canadian author and financial planner, it is estimated that only 15% of all victims of telemarketing fraud ever report it to any law enforcement agency.

Elderly Are Targeted

Con artists know all this, and that's why they relentlessly target senior citizens. Illegal telemarketing operations even share names,

says Jean O'Neil of the National Crime Prevention Bureau in Washington, D.C. That's one reason a person may be victimized repeatedly.

As caregivers, how can we know if our loved ones are being targeted by scam artists? The National Consumers League says some warning signs to watch for include:

- Our parents are receiving lots of junk mail about contests, "free" trips, and prizes.
- They get frequent telemarketing calls about money-making opportunities or asking for donations to charities.
- They have been making repeated payments to out-of-state companies.

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- They receive lots of cheap items like costume jewelry, beauty products, ink pens, etc. (which they may have purchased in order to be eligible to win “valuable prizes” or which may be the “valuable prizes” they supposedly won).

So, how can we help protect our parents from scams like these? Education is the first step.

Aging Parents and Adult Children Together (A/PACT) says that consumers of all ages should know that:

- They can say no.
- They can ask a telemarketer not to call them again, and if that company does call them back, they are breaking the law.
- They have the right to request written information about the product, investment, or charity that they are being asked to purchase or donate to. Legitimate businesses and charities will be happy to send this information.
- They should never give out personal information such as their Social Security number, bank account information, or credit card account numbers to people calling them on the phone.
- If it sounds too good to be true, well, it probably isn't true.

Available Sources Can Help

For more information on common scams and how senior citizens can protect themselves, contact AARP at 888-OUR-AARP and request a free copy of the brochure “The Top Frauds and Scams.”

The National Consumers League also offers a brochure on telemarketing fraud, called “They Can’t Hang Up,” which is

written for older people and their families. You can obtain a copy of this brochure by contacting the National Consumers League at 202-835-3323.

There are further steps you can take.

For example, register with the national “Do Not Call” registry. You can register by calling 888-382-1222 or you can register online at www.donotcall.gov. Registration is free. Registration won't stop all telemarketing calls—you can still be called by charities, political organizations, and some other types of callers—but it will greatly reduce the number of calls received by your loved ones.

You can also remove your name from many national mailing lists by writing to:
Direct Marketing Association
Mail Preference Service
P.O. Box 643
Carmel, NY 10512

What should you do if you suspect your parent has been a victim of fraud? Report it!

You can contact the National Fraud Information Center, which is run by the National Consumers League. Their counselors can refer you to the proper law enforcement agencies. You can call them toll-free at 800-876-7060.

You also can file a complaint with the Consumer Response Center of the Federal Trade Commission by calling 202-FTC-HELP.

Victims of fraud often feel helpless and ashamed. There is, however, a lot that can be done to safeguard our most vulnerable before they are contacted. And if fraud occurs, we can report it to law enforcement agencies that will investigate and arrest, if warranted. ■

Medicare Part D

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Proceed with Caution

If your loved one hasn't chosen a plan yet, don't panic. The deadline for enrollment is May 15. If you and your loved one cannot determine which plan is best, consider enrolling in a plan with a very low monthly premium. This plan can serve as a “placeholder” so a loved one can avoid the penalties that come with late enrollment while shopping for a better plan.

Get Ready, Get Started, Start Filing

Start now to gather all the paperwork related to your loved one's prescription drug plan. Save all receipts for payments made for monthly premiums, deductibles, uncovered drugs and co-pays.

Learn About the Appeals Process

If your loved one requires a medication not covered by his or her chosen plan, then check the plan details for how to file an appeal. Once an appeal is filed, an answer should be forthcoming within 72 hours. Each plan is allowed to create its own variation of an appeals process, so read the plan carefully for details.

Seek Out Allies

Consider joining a caregiver support group or an advocacy organization that meets the needs of elders or family caregivers. You can save a lot of time and headaches by sharing and learning from the experiences of others.

Stein knows that most family caregivers, as with most Medicare beneficiaries, are most concerned about the immediate effect of Medicare D on their loved one's ability to obtain and pay for prescription medications. But she hopes family caregivers will stay aware and become vocal with state and federal legislators regarding current and proposed changes in Medicare.

“After all,” she says, “it's the adult children of today's Medicare beneficiaries are going to be the Medicare beneficiaries of tomorrow.” ■

Paula McCarron has more than 20 years of experience in healthcare including nursing homes and hospice. She lives in Chelmsford, Massachusetts, and can be reached at paulamccarron@gmail.com.

COMING UP IN JANUARY

- Is your elderly a good candidate for a **reverse mortgage** and if so, what should you watch for in helping them arrange one? Guidance on an increasingly popular way to stay independent.
- Practical advice on how to choose a counselor to help **maintain your mental well-being** through the challenges of caregiving.
- Can our aging loved ones continue to **live independently in the face of declining health**? An expert weighs in on a common question.
- Have you looked inside Mom's refrigerator lately? With research pointing to a connection between under-stocked refrigerators and poor health in seniors, you should. **Tips on staying healthy.**

Tips for Caregiver Self-Renewal

By Mandi Caruso



One of the first skills hospice volunteers are taught is self-care in demanding situations.

Supporting the healing work of a dying patient and the patient's family can sap physical, mental and spiritual reserves, whether you are an unprepared friend or volunteer. So, volunteers are taught not only to listen to others without judgment, but also to listen to their own inner dialogues without judgment and with love.

In one exercise of self-love and self-renewal, hospice volunteers are given a

sheet with 25 blank spaces and asked to list all the small, daily tasks that give them moments of peace and pleasure. Volunteers list tasks such as washing and waxing the car, walking the dog, hanging out the laundry, taking a long, hot bath, preparing fishing gear, raking leaves, and more.

Volunteers are then asked to identify what it is in each specific task they named that renews and refreshes them. One volunteer said that hanging out bed sheets in the sunshine and the wind always made her feel that she was being embraced by

her long deceased grandmother. Another volunteer said that digging in the dirt, planting and weeding literally grounded him.

According to hospice training, cataloguing such simple task-pleasures enhances our awareness of our own healing properties and deepens our pleasure in everyday experiences—one of which will someday be our own work of dying. ■

Mandi Caruso lives in Waialua, Hawaii, and can be reached at mandicaruso@hotmail.com.

Someone you know needs this:

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Thick pattern gives feet more traction

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