

# The Caregiver's

## Home Companion

*"Helping Those Who Help Others"*

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### This Month Online

Jean Donahue knows the practical side of caregiving. After all, she has been a family caregiver four times – for both parents and her two children. And over the years, Jean has been called upon by individuals and groups to help share her experience and impart common sense advice on caregiving.

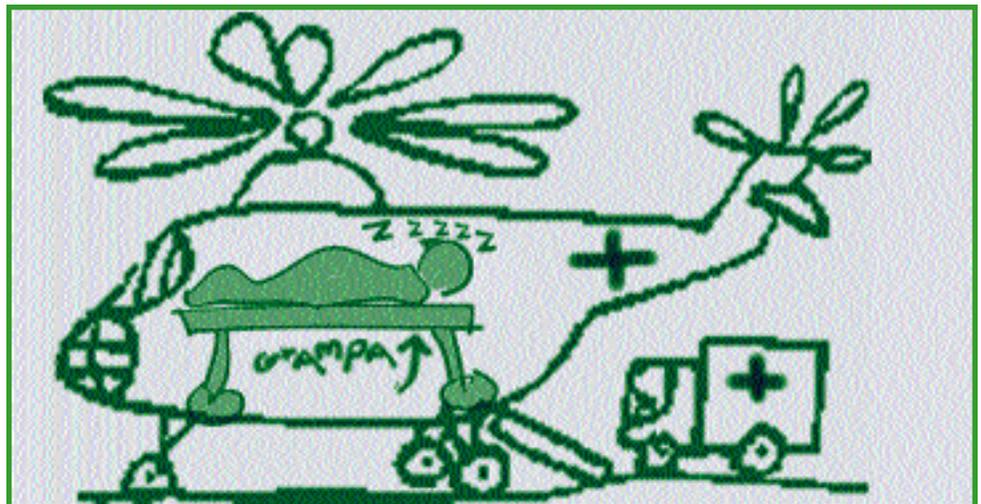
Jean writes our exclusive **Practical Caregiving** column, which is published online at our website [www.caregivershome.com](http://www.caregivershome.com) every Monday. In a relatively short time, **Practical Caregiving** has become the most popular web-only editorial feature on our site. And her e-mailbag at [ASKJEAN@caregivershome.com](mailto:ASKJEAN@caregivershome.com) is brimming with questions and shared experiences, which Jean often uses in her column.

**Practical Caregiving** is the perfect balance for our **Ask an Expert** feature, which allows web visitors to ask advice of appropriate professionals on eldercare and caregiver issues. If you haven't yet checked out **Practical Caregiving**, take a look. There's a growing archive of Jean's columns as well as a new column every week.

## Coping on the Edges of Caregiving

# How to Deal with Your Children Regarding Ill Grandparents

By Paula Sanders McCarron



Do you dread the time when you can no longer put off talking with your child or teen about a grandparent's illness?

If so, you're not alone. Some parents feel inadequate to the task. Some delay out of a hope to protect children from needless worry. Others procrastinate out of fear the conversation will veer to the more uncomfortable topic of death.

What follows are common questions posed by parents with responses by people who speak from years of experience in helping families cope with illness, loss and grief.

*•Do I need to start talking about this now? Isn't it too early?*

"When grandparents are ill, they can no longer be there in the ways they once were for their grandchildren," says Linda Goldman, a grief therapist in Chevy Chase, Maryland, and author of "Life & Loss: A Guide to Help Grieving

Children" (Accelerated Development Inc. 2nd edition, 2000). "As parents spend more time and energy being focused on the needs of an ill grandparent, children and teens feel they are losing their parents as well. Children see and know what is happening. If parents deny anything is wrong, then the child is placed into a conflict between what they see and what they are being told. This leads to a loss of trust."

### So how do I begin?

"Parents should stop thinking and talking like adults," says Dan Schaefer, PhD, from his office in New York. Schaefer is author of "How Do We Tell the Children," (Newmarket Press, 3rd edition, 2002). "We've got to use concrete words when we talk about Grandpa being sick or else children make their own connections which are most often wrong. If Grandpa dies of

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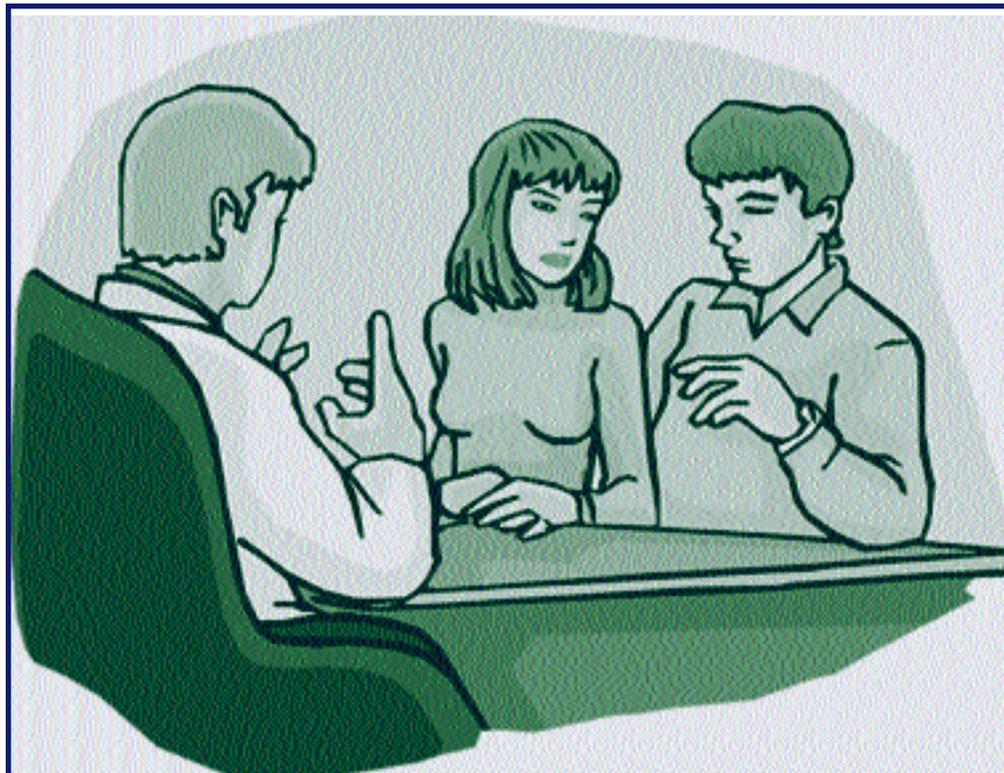
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The Caregiver's Home Companion is produced by caregivers and professional healthcare workers. While this publication is not intended as a substitute for professionally administered medical advice, the practical suggestions, advice and tips made in this newsletter have been tested or reviewed by an individual or organization involved in caring for elderly loved ones. The Caregiver's Home Companion also strives to obtain the input of educators and researchers in all branches of medical and scientific research. We welcome your comments and suggestions at editor@caregivershome.com.

## Helpful Tips for Communicating With Your Loved One's Doctor

By Ursula Furi-Perry



The doctor-patient relationship may be significant, but the liaison between doctor and caregiver is just as important. In order to provide loved ones with the best care possible, caregivers and doctors must maintain good, open communication and work together.

Caregivers are often expected to get the "right" answers from doctors and promptly deliver them to their loved one. Of course, that may be easier said than done — especially when the caregiver lives away from the loved one or the physician is reluctant to cooperate with the caregiver.

Yet maintaining a mutually satisfying physician-caregiver relationship does not have to be like pulling teeth. The following easy steps will lead caregivers in the right direction:

### Meet the doctor

Take time to meet your loved one's medical provider. "Whenever possible, accompany the loved one to an appointment," recommends Mary Beth Salama, member-

ship chairman for the American Academy on Physician and Patient and assistant program director at The Western Pennsylvania Hospital. "Most doctors will likely be grateful and view the caretaker as an additional resource to whom they can turn." If a meeting in person is not feasible, be sure to call the doctor and introduce yourself.

- *Have your permission slip handy*

It's always best to have the loved one's express written permission to access his or her medical records. Signing a Health Care Proxy and Durable Power of Attorney may be necessary, depending on your loved one's condition and wishes, but a letter appointing you as caretaker is almost always imperative. In the least, be sure your loved one verbally alerts the doctor that you will be caring for him/her.

- *Respect your loved one's privacy*

It may seem that a doctor is being uncooperative, but the doctor's reluctance to share

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# Caregiving and Elderly Dental Care: How Important Is It? How to Maintain It?

By Gwen Morrison

You've raised your children, reminding them over and over again: "Brush your teeth," and "Don't forget to floss!" Now, with so many people caring for elderly parents, these same words are echoed through the halls of homes across the country, but not to your children – to your parents.

### Just the Facts

But, how important is it to oversee dental hygiene for our aging parents? According to the American Dental Association, it's very important, and for many reasons. A recent study, by the University of Iowa, recognized that regular dental care to replace missing teeth or preserve denture function may be critical for the elderly in maintaining a balanced diet and consuming adequate amounts of nutrients. Making sure that your loved one's dental health is being taken care of is not just about having fewer cavities – it's about their overall well being, both physically and emotionally.

"Keeping good dental health over a lifetime is important since a healthy mouth plays an important role in speaking, chewing and overall body health," says Diane Persson, Ph.D. LNFA, Center on Aging, School of Nursing at the University of Texas Health Science Center at Houston. "If your loved one's teeth are decaying and falling out, they will most likely be unable to eat properly, speak clearly, and they may be embarrassed to socialize with others."

It's important to note that in a recent survey by The American Dental Association (ADA) and Oral-B Lifetime of Healthy Oral Care, 95% of seniors believe healthy teeth and gums are very important to their overall health. Also important is the fact that approximately 50% of people over 55 have at least 23 of their 32 natural teeth remaining. With studies showing that seniors are taking better care of their teeth in their younger years, and keeping their teeth longer, it's important for caregivers to help maintain the value that their loved ones have placed on their dental health as they age. How can caregivers accomplish this?

"Daily hygiene care of teeth, gums and removable partial or full dentures, is essential in maintaining optimal oral/dental health," says Dr. Bruce Hartley, a cosmetic dentist at Peninsula Center of Cosmetic Dentistry in Los Altos, California. "Brushing with fluoride toothpaste after every meal, flossing once a day, and the use of fluoride mouth rinses will reduce the risk of dental decay and gum disease. Seniors are at increased risk of cavities and gum disease from a condition known as Xerostomia, or dry mouth. Salivary function and output decreases with age, and certain common medications, including heart and blood pressure drugs, induce this syndrome."

Dr. Hartley explains that saliva buffers the acids that cause decay, and with a dry mouth, decay can advance very rapidly. Another contributing factor in deterioration of teeth, and subsequent tooth loss, is that older persons have less nerve tissue in their teeth. Because of this, your loved one may not know he is experiencing severe tooth decay – there may be no pain or discomfort involved.

As a caregiver, it will be up to you to ensure that your loved one visits a dentist on a regular basis to check for any signs of decay. Sometimes dentists have seniors visit every three months for a professional cleaning to be sure that the teeth are staying healthy.

### Educating Yourself

If your loved one is not able to manage his own dental care, it will be up to you to assume this responsibility for him. But keep in mind that there are advances in dental products that make it easier for seniors. Do some research; ask your dentist. Even if your loved one has lost some manual dexterity, there are products available to make it easier for them to brush their own teeth. Not only does this help you, the caregiver, it helps your loved one maintain control of that part of his life.

Dr. Steven E. Roth, DMD, a dentist at Fishman Roth Associates in New York City, says that when it comes to eldercare there are several important considerations.

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### Timely Tip

Beans are a great source of fiber for the elderly, but some avoid them because of unpleasant side effects. Beans' side effects can be minimized by rinsing them thoroughly with running water and including them with a varying diet of other high-fiber foods. High-fiber foods include apples, berries, bran muffins, broccoli, brown rice, brussel sprouts, cauliflower, carrots, figs, multi-grain cereals, oatmeal, oranges and pears. Set a goal of 20-30 total grams of fiber per day.

**If your loved one is not able to manage his own dental care, it will be up to you to assume this responsibility for him. But keep in mind that there are advances in dental products that make it easier for seniors.**

## Caregiving and Elderly Dental Care

Continued from Page 3

"Assess the level of cognitive ability," he says. "Is that patient suffering from any mental illnesses?"

Dr. Roth says caregivers should also note the level of any physical handicap. If the patient has Parkinson's or has suffered a stroke, the caregiver must assess whether their loved one is able to clean their own teeth.

"We have a quote that hangs in our office from Dr. Charles Mayo of the Mayo Clinic – 'Preventive Dentistry can extend your life by 10 years,'" says Roth. "We strongly believe in this because there is research that shows that the presence of gum disease can contribute to the risk of stroke and heart attack and diabetes. Missing teeth and wearing dentures contributes to poor digestion. Missing teeth also dramatically affect self-esteem which is important at any age."

### Tips for Dental Care

For caregivers who are in a position where they have to physically assist their loved one with oral hygiene and dental care, the ADA offers these tips:

- *Choose a well-lit, convenient location.*

If the person is uncooperative or uncontrollable, try to calm him or her by explaining what you are about to do, or schedule the task for a time of day when the person is more rested or may be more receptive.

- *Move in a calm, slow, reassuring manner to avoid startling the person.*

Give verbal praise and reinforce independent attempts at care.

- *Support the person's head, and take special care to prevent choking or gagging when the head is tilted back.*

If the person is unable or unwilling to keep their mouth open, you can make a mouth prop can by taping several tongue blades together. Discuss with your dentist how to insert a mouth prop to avoid injury to teeth.

*Gwen Morrison is a frequent contributor to this publication. She lives in Lawrenceville, Georgia, and can be reached at [gwen@gwenmorrison.com](mailto:gwen@gwenmorrison.com).*

### Timely Tip

Alzheimer's progression is often accompanied by incontinence, and the reason is often more environmental than physical.

Patients may forget where the bathroom is located and have trouble getting there in time. You can help by posting a picture of a toilet on the bathroom door. Once inside, zippers and buttons can pose more problems for Alzheimer's patients. Consider switching their clothing to elastic-waist pants.

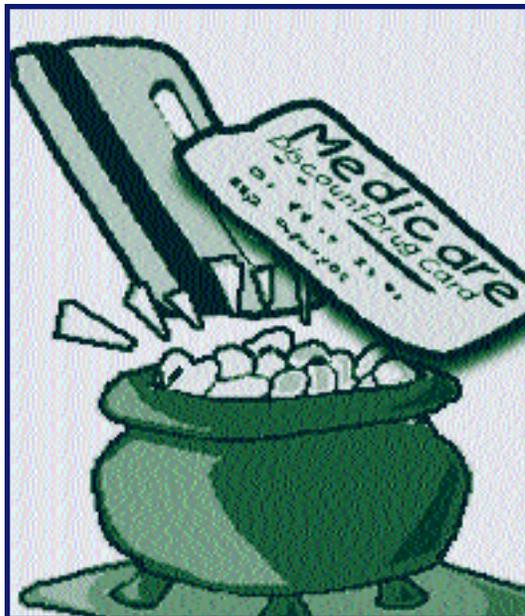
## The Medicare Discount Drug Card:

### Will It Work For You?

By Barbara Krasnoff

If you follow the news at all, you've probably heard about the Medicare Prescription Drug Improvement and Modernization Act of 2003. This act, which was signed into law on December 8, 2003, amid great controversy, will radically change the administration of Medicare benefits beginning in 2006.

Because Congress didn't want Medicare beneficiaries to have to wait two years for relief on prescription drug purchases, they included an intermediate benefit that will start in June of this year: Medicare-approved drug discount cards.



The idea is to provide immediate savings on prescription drugs for seniors and others on Medicare. According to the U.S. Department of Health and Human Services, seniors and individuals with disabilities will be able to use these cards to get discounts on a variety of medications.

The cards will be offered by pharmacies, insurers, companies that already offer discount cards, Medicare private plans, and other private organizations. The Centers for

Medicare and Medicaid Services (CMS), which is administering the program, took bids by companies who wanted to become part of the program (in

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## The Medicare Discount Drug Card

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fact, bids were due January 7, 2004). Companies that are accepted will offer Medicare-sanctioned discount cards that will be accepted by specific pharmacies nationwide, and which will offer discounts on a variety of medications.

As a caregiver, this program has far-reaching implications for you and your elderly loved one. But how effective will this program actually be? A lot depends on your parents' income, on whether they already belong to a prescription drug program, and on the effectiveness of the companies that will be offering the cards. In order to try to clarify what is a pretty complicated program, here is a Q&A which will, hopefully, answer most (if not all) of your questions.

- *When can my parents enroll?*

People will be able to enroll starting in May, 2004; the program itself is scheduled to start in June, 2004.

- *Who is eligible for the drug discount card?*

Most Medicare beneficiaries are eligible for the discount card. They are not eligible if they already have other prescription plans, including:

- ✓ Outpatient prescription drug benefits under your state Medicaid program
- ✓ TRICARE (military health insurance)
- ✓ FEHBP (health insurance for Federal employees or retirees)
- ✓ Any other employer or retiree plans that include prescription drugs.

- *How much will my parents save on medications?*

According to the CMS, they should save about 10% to 15% on their total drug costs, with savings of up to 25% on individual prescriptions. (These savings may be augmented by other non-government programs, such as Merck's plan to offer free medicines to the lowest-income holders of the Medicare discount drug card.)

- *Is that all?*

No — there is an additional benefit for low-income beneficiaries. If your parents' income falls below 135% of the poverty line (\$12,123 for single individuals or \$16,362 for married individuals in 2003), then they may be eligible for an additional annual benefit of \$600. The \$600 would be applied through the discount card toward prescription drug purchases — in other words, it would work like

a debit card. When your parent gives the card to the pharmacy, the appropriate amount would be subtracted.

- *Can my parents apply for the \$600 at any time?*

They can apply for the first year's \$600 benefit at any time during 2004. However, if they are late enrolling for the benefit in 2005, they will lose part of the benefit — the amount will be reduced by \$150 every quarter, starting in April, 2005.

- *So if my parents do qualify for the \$600, that means they would not have to pay for certain drugs at all — right?*

Not exactly. There will be a 5% co-insurance for those at or below 100% of the poverty line, and a 10% co-insurance for those above 100% of the poverty line.

- *What kind of drugs will the benefit cover?*

According to the CMS, nearly all prescription drugs that can be purchased at retail pharmacies are eligible for discounts and for use of the additional \$600 benefit. These include syringes and medical supplies associated with the injection of insulin. Some over-the-counter medications may also be discounted (although they cannot be part of the \$600 benefit).

However, which drugs are included, and what the discount will be — and which pharmacy will take the card — depends on the specific program your parent belongs to. If he or she takes more than one medication, there is no guarantee that the other medications will also be covered.

- *Will the same medications always be covered by my discount card? Will the prices remain the same?*

No to both questions. A discount card supplier can update its prices and the list of drugs that it covers on a weekly basis. The CMS says that it will monitor drug prices to make sure prices aren't raised without reason. (A good reason is that wholesale prices rise. A bad reason is that the supplier simply wants to increase its profit margin.)

- *How about if my parent joins more than one program?*

Sorry, but your parent can only join one program at a time. (This only applies to the Medicare-sponsored programs; it doesn't apply to private discount card programs.)

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### Timely Tip

Winter and the elderly can be a deadly combination as seniors turn down thermostats to save money on heating. This can lead to hypothermia, which can kill if the body temperature drops for a prolonged period. This is a particular problem for elderly who lack proper nutrition, take certain medications, drink alcohol or suffer from arthritis, Alzheimer's or Parkinson's disease. Watch for tell-tale signs of hypothermia such as stumbling, fumbling or incoherent speech. Take the person's temperature and seek emergency help if their temperature is 96 or lower. And check the thermostat whenever you visit.

## Tips for Communicating with Your Loved One's Doctor

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### Timely Tip

Caregiving is an absorbing role. You need time out of the house, but before you leave your elderly alone for even a short time, answer these questions:

Can your loved one call 911 or neighbors in an emergency?

If they're hungry, can they prepare a meal safely without assistance?

Can they use the bathroom without your help?

In case of emergency, are they capable of leaving the house and seeking safety outside?

Are they aware of smoke alarms and unusual noises, or will they tend to ignore such sounds?

If you answer "yes" to these and any other individual questions, by all means get out for a break. If you can't answer "yes," seek temporary assistance so you still can get away.

**Have a network of people available for help in order to avoid burnout. Siblings, extended family and friends may be available to meet and talk with medical providers and take your loved one to doctor appointments....make sure the doctor's office has permission to talk to each new person.**

information may be due to new laws. "With new HIPAA regulations in effect, medical providers are being more careful about what they say and to whom," Salama explains. Set boundaries: have a discussion with the doctor and your loved one about the type and amount of information that is going to be shared.

- *Discuss important medical decisions with your loved one before talking to the doctor*

"Talk to the patient about certain medical situations and be informed about his or her preferences should those situations arise," advises Salama. Take the opportunity to communicate, and make sure to update your discussions as necessary. It is always best to cover these issues before you and your loved one are in a crisis mode.

- *Be firm without being pushy*

Ask pointed questions; it may help to gather your thoughts and outline your questions before a visit or phone call to the doctor. Insist on getting real answers, but bear in mind that they may not always be the answers you want. Be sure to ask your loved one for his or her input — are there certain questions your loved one would like to ask? Is there new information that needs to be relayed to the doctor?

### Stay in the loop

Check in with the doctor periodically. Whenever possible, set up a regular time to discuss your loved one's condition, progress and needs. If it's feasible, meet with the doctor along with your loved one or have a conference call among the three of you. This will help avoid miscommunication and encourage dialogue between all involved.

- *Look out for your loved one's best interest*

Does the doctor seem to know your loved one? Does he understand his or her medical

status? Does the doctor offer comprehensive help and advice to you and your loved one? Does he use language that's easily understood? Is the doctor's staff easily accessible and readily available to help? Those are all important issues. Take time to assess your loved one's compatibility with the doctor and the lines of communication that exist between them.

- *Round up the minions*

Have a network of people available for help in order to avoid burnout. Siblings, extended family and friends may be available to meet and talk with medical providers and take your loved one to doctor appointments. In any case, make sure the doctor's office has permission to talk to each new person. If you live far from your loved one, it may be practical to hire an assistant who can represent your loved one at the doctor's office, Salama suggests. "In that case, be sure the assistant is compatible and will cooperate with not only the patient, but also the doctor."

- *Contact patient interest organizations for help*

Organizations like the American Academy on Physician and Patient ([www.physicianpatient.org](http://www.physicianpatient.org)) exist to foster good communication between doctors and the people they serve. "Physicians are trying hard to make communication with patients the touchstone," Salama says. "These organizations keep track of doctors who are accessible and maintain good relationships with their patients." When in a bind, don't hesitate to call patient interest organizations for help, answers to questions, and recommendations for patient-friendly physicians.

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## Dealing with Your Children Regarding Ill Grandparents

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pneumonia and the child is told Grandpa was sick or died because of the cough, then what will the child think when Dad is sick with a cold?"

Schaefer says, "The younger the child, the more very, very, very's you have to use. Don't just say Grandpa was sick but say Grandpa was very, very, very sick."

• *But how do I know I'm saying the right thing?*

According to Goldman, parents should focus more on listening than worrying about what to say. She would have parents ask, "What do you think is happening? What is it you'd like to know? How would you like to help?"

• *Should I encourage my child to be helping?*

"It's important for children to be part of the team," says Goldman. She gives the example of a young girl patient who drew a picture of her ill grandmother lying in bed. The girl talked about how she would watch television with her grandmother, bring her something to drink and draw pictures for her. By talking about these actions, Goldman was able to assure the girl that she was still an important part of her ill grandmother's life. "She knew her efforts were valued and appreciated. Children need to be included in helping. Just let them choose how they want to participate."

• *But what if my child doesn't want to visit a grandparent who is ill?*

Goldman encourages parents to give children and teens choices by asking, "Do you want to visit today? How long do you want to stay? What can I do to help make this easier for you?"

Children and teens can also be involved in other ways such as making phone calls or sending along a plate of favorite cookies. Making memory books, capturing special stories on tape or creating art or music can also be ways to show they care.

### What about my teenager?

Donna Stephens, coordinator of Forget-Me-Not, a grief support program for children and teens in Anchorage, Alaska, points out adolescents are able to intellectually understand the biology of death, but may not be able to place death in a context of personal meaning or spiritual integration. Teenagers can also have conflicting emotions when they are asked to be more connected and involved with their family at the same time they are struggling to gain

more autonomy and independence.

In fact, parents should not be surprised if teens emotionally withdraw or spend less time at home during the time of an illness. Parents need to keep this act of withdrawal in perspective, acknowledging in a positive manner what teens are emotionally capable of contributing rather than focusing upon what teens cannot handle.

• *What if my child or teen starts to act out?*

"There are times when children and teens will refuse to comply with adult requests, make deliberate attempts to annoy or upset people, and blame others. Grieving children and teens behave in these manners in an attempt to re-establish stability in their turned-upside-down worlds," says Stephens.

She adds, "Do get help immediately if your child or teen expresses persistent self-blame or guilt, an overall sense of unworthiness, has self-destructive behaviors or expresses a desire to die."

• *What is the most important message in all of this?*

"You have to completely take it off the table that the child is in any way responsible for this happening," says Schaefer. "They may truly believe they have caused the illness."

Goldman says she has yet to meet a child who didn't blurt out at some point, "I know I made it happen."

• *I'm still not sure it's the right time for all of this.*

It's probably never going to be easy to start this conversation. But as Schaefer asks, "What are you going to do later if you don't start talking about it now?"

No matter how difficult it is to start these conversations, it's important to know that parents can help their children and teens cope with the changes, emotions and losses brought about by illness or pending death and are really equipping their children to be better prepared for life.

*Paula Sanders McCarron is a writer and poet living in Anchorage, Alaska. She has more than 20 years of experience in healthcare, including nursing homes, hospice and healthcare and can be reached at [pmscustomcpu.com](mailto:pmscustomcpu.com).*

## Grieving Guidelines

*These guidelines are for families grieving together, young and old alike:*

•  
Death, change, loss and grief are all part of the normal, developmental life span.

•  
Listen to heal things that cannot be fixed.

•  
Remembering is reassuring.

•  
Routine is stabilizing.

•  
Use concrete words.

•  
There is no one right way to grieve.

•  
Trust the griever.

•  
Living joyfully and meaningfully does not mean we forget.

## The Medicare Discount Drug Card Continued from Page 5

### **Timely Tip:**

Thick or chewy foods aren't the only source of swallowing problems in the elderly. Sometimes it is food or liquids that are too thin and become difficult to swallow properly. Try a thickener that mixes with drinks or thin foods to give them more consistency. Adjust the thickness to the consistency necessary. These are over-the-counter products such as Thicken Right Instant Food Thickener, from Diamond Crystal.

**The discount card program was only meant to be a temporary stopgap. In January, 2006, the Medicare Prescription Drug Improvement and Modernization Act of 2003 goes into effect, with a whole new set of programs.**

- Can my parents switch programs if we're unhappy with the one they're in?

They can change which program they're in during 2005, but they can only make this switch between November 14 and December 31, 2004. They can also change in certain special circumstances; for example, if they move to a long-term care facility, or if they move to an area not served by their current plan.

- *Do Medicare recipients have to join the discount card program?*

No. This is a totally voluntary program.

- *Will my parents have to pay a fee to belong?*

There can be an enrollment fee of up to \$30 per year (the fee is waived if they qualify for the \$600 benefit). It depends on what, if anything, the supplier wants to charge.

- *What happens in 2006?*

The discount card program was only meant to be a temporary stopgap. In January, 2006, the Medicare Prescription Drug Improvement and Modernization Act of 2003 goes into effect, with a whole new set of programs. Stay tuned.

For more information, you can contact Medicare via the program's website at [www.medicare.gov](http://www.medicare.gov) and click on: "Prescription Drug and Other Assistance Programs" or by phoning toll free (800) MEDICARE (800-633-4227).

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# The Caregiver's Home Companion

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### **Upcoming in March**

- Power of attorney – what is it and why is it so important for caregivers and their loved ones? An elder-law attorney explains.
- How I Cope: A daughter's account of how she learned about the benefits of adult day care and got her parents to embrace it after months of resistance.
- Our growing elderly population, with its illnesses and other medical conditions, has spawned a blossoming industry for unique and specially designed clothing and footwear that makes everyday life easier for seniors and caregivers alike.
- Certain diseases in the elderly call for special diets rich in nutrition. A registered dietician coaches caregivers on healthy diets that work particularly well with certain diseases.