

The Caregiver's

Home Companion

"Helping Those Who Help Others"

Inside this Issue:

- New Year Rings in New Concerns for Caregivers 2
- Helping Families Deal with the End of Life 3
- Coming Back to Crock Pots for Easy Nutrition 4

This Month Online

I Am A Caregiver

Caregivers are the unsung heroes of this generation. But what makes a caregiver? Who is a caregiver? How do caregivers find the fortitude to carry on, when all of life's demands seem to teem around them? Caregivers have their own chance to answer these questions as we draw a profile of the family caregiver at our site www.caregivershome.com. *The Caregiver's Home Companion* is running a subscription sweepstakes for site visitors who tell us what characteristics make up the 21st century family caregiver. Check out the site for more details. Submissions close February 24.

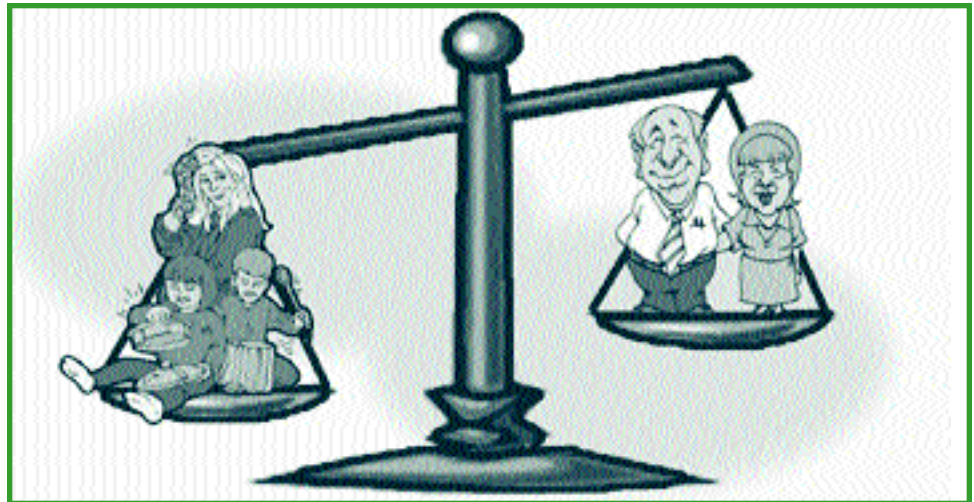
On the Internet Airwaves

Chris Pederson, founder and publisher of *The Caregiver's Home Companion* and www.caregivershome.com, will be interviewed January 24 at 6 p.m. EST on the nationwide radio program "Coping with Caregiving" on the largest online radio network, wsRadio. Chris will be interviewed by host Jacqueline Marcel regarding the quest to meet the myriad needs of caregivers amidst the field's explosive growth. You can hear the interview live at www.wsradio.com/copingwithcaregiving/ or you can hear a tape of the program at the same address beginning January 26.

Can You Do it All?

Caring for Your Family and an Aging Loved One

By Gwen Morrison



If you're one of the millions of Americans who cares for an aging loved one in your home or theirs, and if you're raising a family of your own while juggling the demands of a career, you're probably finding it difficult to strike a balance.

According to the National Center on Caregiving, one of every four U.S. households —22.4 million— is involved in caregiving for someone over the age of 50, and those caregivers are spending an average of nearly 18 hours per week providing care to those loved ones. That's in addition to life's other everyday demands.

It's important for caregivers to remember that they can't possibly "do it all." Organizing your life to accommodate all those people in it who are in need and deserving of care and attention can be difficult, but with a little help and a lot of communication, it can be done.

Organization, communication and a

willingness to ask for help are often keys to successful management of any situation. It's no different when it comes to balancing the care of your family, your loved one and yourself. You must make time for all of it, or something unfortunately will have to give.

Setting the Stage for Success

Marcia L. Martin, Ph.D., LSW, co-dean and professor at Bryn Mawr College in Bryn Mawr, Pennsylvania, feels strongly that in order for a caregiver to manage both a family of their own and care for an aging loved one, it is important to seek outside assistance wherever possible. "Even for a few hours," she says. "The older adult can go to a community respite care facility for an afternoon, in order to allow you individual time with the children."

Plan special times of the day that are allocated just for that one child – read a

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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.

Changes in Mom and Dad

New Year Rings in New Concerns for Caregivers

By Paula Sanders McCarron



The end of the holiday season signals the start of a new year but for family members who made a visit to aging or ill loved ones over these recent weeks, the end of the holiday season may also be the start of a journey into caregiving.

According to a study by the National Council on the Aging and Pew Charitable Trusts, there will be 15 million long-distance family caregivers by the year 2012, twice as many as were identified in 1997.

While the study defined a long-distance caregiver as an individual providing or managing care for a loved one, age 55 or older, it was found that on average, long-distance caregivers travel 300 miles and for four hours to reach their loved ones.

The holidays present an opportunity for family members to spend extended time with each other and to observe the kinds of challenges and problems which can go undetected or unreported in phone conversations. During a holiday visit with a loved one, you may have been surprised to see piles of unopened mail or shut off notices for unpaid utility bills or to learn your loved one is carrying unusually high balances on credit card statements due to new purchases or late fees. Maybe you found spoiled food in the refrigerator or no food at all. Did you notice outdated or unopened pill bottles on the shelves of the medicine cabinet? Or maybe you were

aware of a dramatic weight change, periods of confusion, increased forgetfulness or an unsteady gait?

If you came home from your holiday visit concerned enough to pick up the phone and inquire about care for your loved one, you weren't the only one. The Eldercare Locator, a federally funded information and referral service has watched its call volume increase for the past several years by 25% during December and January. In fact, the service now staffs for the increased calls and conducts specific training for responding to post-holiday callers.

Many family caregivers are not only concerned about what they observed during a holiday visit but also fear what may lie ahead for a loved one. It's all too easy to imagine a loved one will forget to take medications, fall prey to a financial scam, leave the oven on, suffer a fall, skip meals or have a serious car accident.

"Stop imagining the worst and start dealing with facts, not fiction," is the advice of Joy Loverde, a long-distance caregiver living in Chicago. Loverde is involved in the care of her mother who resides in Florida and is also the author of *The Complete Eldercare Planner* (Three Rivers Press, 2nd Edition, 2000). Loverde describes herself as a "typical long-distance caregiver" who knows how easy it can be to speculate on what

Continued on Page 6

The Hospice Movement

Helping Families Deal With the End of Life

By Barbara Krasnoff

When a woman from a local hospice program first showed up at the hospital to talk about my father's care, my reaction was first to send her away. Hospice, I thought, meant giving up, and we were certainly not going to do that.

What I didn't know was that I was laboring under one of the main misconceptions about the Hospice program. According to the Hospice Foundation of America (HFA), an educational foundation that provides education to and support for hospices throughout the country, it means instead that you are doing everything you can for a patient whose illness cannot be cured. This includes handling pain, providing support for the family, and trying to enable the patient to live as comfortably, and as close to normally, as possible.

"Hospice is a holistic philosophy to deliver care to dying persons and their families," explains Dr. Ken Doka, Senior Consultant to the HFA. "It's based on good palliative care and symptom control. The heart of the philosophy is letting people live as long as they have."

The hospice movement was started in 1967 by Dr. Cicely Saunders, a British physician. Dr. Saunders wanted to change a situation where people suffering from cancer and other severe diseases died in hospitals instead of their own homes, where doctors saw death as failure, and where physical pain was not alleviated because painkillers were considered too dangerous or addictive.

As a result, Dr. Saunders helped found St. Christopher's Hospice in south London, which concentrated on the comfort of the patient, both physically and emotionally, and the participation of the patient's family. The movement soon spread to the U.S., and today, according to the HFA, there are more



than 3,100 hospice programs in the United States.

How It Works

Most families are introduced to hospice care in the hospital by a social worker, who will approach them after physicians have determined that the patient may be approaching the end of his or her life. There is no one single hospice organization — depending on where you live, there could be one or more programs available. These programs are accredited by the Joint Commission on Accreditation of Healthcare Organizations, so you can check them out by going to the JCAHO website at www.jcaho.org.

How are they funded? These programs are covered under Medicare (and, in most states, under Medicaid) once a physician has certified that the patient has a prognosis of six months or less. Many insurance programs also cover hospice services.

Once a family has joined the hospice program, a plan of care is developed that takes into consideration pain and comfort levels, support systems, financial and insurance resources, medications and equipment needs. Services can include home health aides, medical appliances (my family, for example, received a hospital bed and a wheelchair, among other things), and counseling.

"Unlike most medical institutions which look at the patient as the unit of care, hospice really looks at the family as the unit of care," Dr. Doka explains. "It looks at how we can help this family as they struggle with the terminal illness of a family member."

Families should be aware that a specific hospice program may have some limitations depending on what the local organization can offer. For example, while hospice tries to make it possible for a patient to live comfortably in his or her own home, that is some-

Continued on Page 4

Timely Tip:

If you are caregiving for a parent and your siblings are also involved, you will streamline some of your caregiving responsibilities by keeping everyone interested involved and up-to-date. You can do this by meeting often as a family, either in person or by conference call. Discussing each person's caregiving responsibilities, problems and feelings may help defuse tensions and prevent problems. If your family meetings tend to turn into arguments, ask a clergy member, professional counselor or family attorney to moderate.

Helping Families Deal With the End of Life Continued from Page 3

times not possible — but not all hospice programs have separate facilities available. There is also a chance that your current physician may not be a part of the hospice program. However, most hospice programs try to be flexible. According to hospice representatives, hospice physicians work closely with your doctor of choice to determine a plan of care.

If you decide to opt for a course of treatment that is outside the hospice program (a clinical trial, for example) you would have to leave the hospice program. However, you can return if you need to. One of the factors that convinced my mother and I that we could safely join hospice was the representative's assurance that, if my father began to recover, we could leave the program at any time, and rejoin if it was needed.

Making a Difference

What kind of a difference can hospice make? That depends, of course, on your needs. For my family, hospice meant that my father's medications were delivered directly to the house whenever he needed

them. We also had a 24-hour hotline to call if we had any questions or emergencies. In fact, when my father fell from his chair one evening, we were able to call a nurse who asked a few questions, told us the safest way to get him back into bed, reassured us there was no harm done, and had a medical professional show up the next day to make sure. There also was a psychologist available to talk to my father by phone and help him deal with his situation.

And it meant that there was a grief counseling group for my mother for the year after my father's death — a group that proved so helpful to its participants that, two years later, they all still meet informally once a month at each other's homes.

"I think we all have images of how we'd like to face the end of life," says Dr. Doka, "and hospice allows you to turn those images into reality."

Barbara Krasnoff is a writer and former caregiver living in Brooklyn, N.Y. She can be reached through an email sent to editor@caregivershome.com.

Timely Tip:

Caregivers can help their loved ones avoid choking hazards when eating if they avoid serving certain foods that can cause choking: steak (the leading food cause of choking), dry foods that break into small pieces like seeds, nuts or baked goods; foods that can irritate a sensitive throat, such as vinegar or salty potato chips. Remember that the aging throat generally becomes more sensitive naturally and that necessary medications can irritate it.

Caregiver's Helper

Coming Back to Crock Pots for Easy Nutrition

By Sharon Palmer, RD

Who has time to cook?

If you're a caregiver, your daily schedule probably looks something like this: go shopping, do the laundry, clean the bathroom, pay the bills, call the insurance company, drive to the doctor's appointment, call the dentist to make an appointment, pick up the new prescription at the pharmacy, and give a bath before dinner. Not to mention the endless list of chores involved in taking care of your own business.

There may be little time in between these tasks to fit in the simple, essential duty of cooking meals. More than 80% of caregivers report that they are suffering from high stress levels, so you're not alone.

Yet food preparation is one of the caregiver's primary tasks every day. Eating healthfully is not only important for your loved one, but it is essential to keep your own body fueled so that it can meet the demands of a rigorous schedule. Poor nutrition will eventually take its toll on the body of your loved one as well as your own.

So try taking a short cut to good nutrition.

Pull out the crock pot from the farthest corner of the cabinet, blow off the dust and get cooking one-pot meals. Toss the ingredients into the crock pot when you have a few minutes during the morning and by dinner, voila! You've got a hot, nutritious meal that tastes like you've been slaving over the stove all day.

One-pot meals have been around since the beginning of mankind, when early tribes stirred their fired-clay vessels over the open fire, stewing whatever game and plants they were lucky enough to harvest that day. These simple, hearty one pot dishes continued to nourish folks throughout history, from the suspended blackened cauldrons of The Middle Ages to the cast iron stew pots bubbling on wood burning stoves at the turn of the last century.

The single pot cooking style reached its stirring spoon across the globe, as it is easily glimpsed in Indian stews and sauces, North African couscous, Spanish paellas, Italian pastas, British pot roast dinners, and Cajun/Creole cuisine of jambalayas and

Continued on Page 5

Coming Back to Crock Pots Continued from Page 4

gumbos. People have long known that the most efficient method of cooking is to throw it all into one pot, step back, and let the pot do its job of nurturing the ingredients to blend into a flavorful, nutritious mélange.

In today's crock pots, slow cookers, and oversized cooking pots, we can achieve the same results our ancestors did long ago. As we throw our ingredients into the crock pot and turn the dial to low, so they tossed similar ingredients into a rustic pot hanging from a stick over a fire thousands of years ago. We turn our backs on the slow cooker to accomplish a myriad of tasks that await us, returning to open the lid hours later, if only to breathe in the flavorful fumes and stir the contents once or twice, a ritual that our ancestors may have performed kneeling before the fire pit.

Not only does one-pot cooking save considerable production time, it also reduces the effort. When making a single-pot roast dinner, you don't have to heat up the entire oven to cook the ingredients. When preparing a one-pot stew, you are not required to sear a steak in a skillet, boil some potatoes, and steam a vegetable separately – each task consuming its own amount of energy. Of course, the primary energy expenditure that is saved is the caregiver's labor. The production savings extend beyond preparation time, as clean up time is significantly reduced. After all, there's only one pot to clean up, not a multitude of cooking utensils.

Often one-pot cooking can rely on standard household ingredients, so you are not required to run out to the store for an essential item or make a long shopping list detailing ingredients. These meals can incorporate canned, frozen and nonperishable goods, like frozen or canned vegetables, dried rice, barley, or pasta, frozen or canned meats, or canned or dried beans.

A one-pot meal by definition should provide a serving from the major food groups all in one package, a protein source, starch/carbohydrate source, and vegetable source. Savory beef stew with potatoes and carrots, chicken and dumplings with peas, and chili con carne with corn are examples of combining the food groups effectively.



One-pot cooking can be a healthful method of cooking, also. Because crock pots cook at low temperatures and foods rarely stick to their surfaces, it is not necessary to add additional fat for cooking. Keep in mind that when grilling meats, the fat is allowed to drip off of the meat, thus reducing fat intake. But in stewing, the fats remain in the product.

It is important to try to choose lean cuts of meat and poultry to begin with. Remove the skin from poultry products before cooking them, as most of the fat resides in and under the skin. Trim all visible fat from red meat cuts before cooking. You don't need to add large amounts of salt to slow cooked meals, as these dishes are very flavorful due to the stewing process. Use herbs and spices liberally to

assist in establishing a hearty flavor while limiting the use of salt, salted broth mixes and seasoning salts if you are concerned about sodium intake.

Most one-pot dishes are moist and stewy in texture, which requires the addition of a liquid. Try adding fat free, low salt broths, canned tomatoes or tomato sauce, or fat free milk for healthful liquids to bring moisture to the pot.

Slow cooked meals are also very tender and easy to swallow, a great benefit in feeding the elderly. Allow the flavors to blend and bubble, open the lid occasionally to stir the contents and enjoy the aroma. This will stimulate your household's appetite and fill it with the smells of a good, home cooked meal. It will smell and taste as if you've been spending all day cooking when you haven't.

(Visit our website www.caregivershome.com under the News & Info tab for crockpot recipes and a selection of examples from the food groups.)

Sharon Palmer is a registered dietician and writer who has managed healthcare food and nutrition departments for 16 years. She is a member of our Board of Experts in the Ask an Expert section of our website. She lives in Southern California and can be reached at spalmer952@earthlink.net.

Timely Tip:

One of the greater risks for Alzheimer's patients is wandering or roaming away from their residence. Since perception often is affected by the illness, you can make it difficult for your loved one to walk away if you "camouflage" your doors by painting them the same color as your walls.

And if the Alzheimer's patient does locate the door, you can slow their exit, or stymie it altogether, by placing plastic covers over door knobs. These covers are typically found in children's stores and are sold to prevent toddlers from opening doors.

New Year Rings in New Concerns for Caregivers Continued from Page 2

If you go directly to your loved one with your concerns, you may find your loved one will respond with denial that anything is wrong — it is easier to open conversations by sticking with questions. “Rather than telling my mother what I think needs to be done, I ask her...”

Timely Tip:

Seniors develop a difficult time swallowing as they continue to age, and certain diseases, such as Parkinson's, complicate the situation. What seems simple (swallowing), is actually a very complex process. If you notice this problem in your loved one, ask their doctor for a referral to a speech/language pathologist (SLP), along with a prescription for swallowing evaluation and therapy. An SLP conducts a swallowing study and a video fluoroscopic evaluation to determine what is causing the problem and recommends treatment. As a caregiver, it will often fall to you to be alert to a problem and initiate this process.

might happen rather than dealing with what is happening for a loved one.

As a first step in “dealing with facts,” Loverde suggests talking with others who either see your loved one regularly or who were present during the time of your visit. “Ask questions like, ‘Did you see the dents in Dad’s car?’ Don’t say, ‘Do you think Mom has dementia?’ As family members, it is not our job to diagnose but to report facts that will help others to do their job.”

If you go directly to your loved one with your concerns, you may find your loved one will respond with denial that anything is wrong — or worse, with hostility. For this reason, Loverde says she has found it easier to open conversations by sticking with questions. “Rather than telling my mother what I think needs to be done, I ask her, ‘Have you given any thought to what you’d want to do in the event you ever need more care?’ Or I ask for her advice. I might say, ‘I’m thinking about how to prepare for my retirement. What kinds of things did you do?’”

Loverde believes a discussion about money and insurance matters is critical. “It comes down to who is going to pay for what. What are the resources? Does your family member have long-term care insurance? What kind of coverage does a loved one have for home care? Assisted living?”

If a loved one does not have the means or insurance coverage to pay for in-home care or assisted living care, you might be thinking it would be much easier for all concerned to have your loved one move into your home. “Really give some thought before moving a loved one,” says Loverde. “Is your family emotionally and financially stable enough to handle this? Very few people can handle living under the same roof. And what if it doesn’t work out, how do you ask a loved one to move out?”

If thinking about all of this threatens to put you into a post-holiday funk, don’t despair just yet. Loverde suggests a second visit

with your loved one might be a good idea. “It’s like you’re behind the 8-ball and now you’re trying to catch up. But no matter what you do, follow-up is key,” she adds.

To get started, you might want to get a notebook to keep track of lists and hold on to copies of interesting articles or forms needed for insurance claims. As you gain more information, the notebook can be a good place to keep a phone list of your loved one’s neighbors, friends, and healthcare providers.

Other first steps can include learning about community resources, Medicare, Medicaid or other insurance plans. You may want to talk with your employer about long-term care coverage, employee assistance programs or leave policies for family caregivers.

By taking action and becoming more knowledgeable, you’ll likely discover new avenues for your caregiving challenges ahead as well as become more creative in finding the best solutions to meet the needs of your loved one.

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 homecare and can be reached at psmcustomcpu.com.

For more information on this topic, check out these resources:

Home for the Holidays: Ten Warning Signs Your Older Family Member May Need Help. Available both on the website and in printable form as a brochure at www.n4a.org/locator_holiday_manual_021220.cfm

To locate local resources for elders, contact Eldercare Locator (800) 677-1116 or www.eldercare.gov.

Handbook for Long-distance Caregivers. A free printable manual from the Family Caregiver Alliance at www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1034.

Caring for Your Family and an Aging Loved One Continued from Page 1

book together, do a puzzle, build a town out of Legos. Whatever it is, be sure that it's during a time when you are less likely to be interrupted by others who are in need of your assistance.

Organize the day to include time for everyone – especially for yourself. If you're not taking care of yourself first, everyone around you will ultimately suffer.

Communities across the country offer resources to families who care for their elderly parents. Churches provide play-groups for children, giving parents time to tend to other necessary appointments through the day. Don't try to do too much – take time off from both caring for your children *and* caring for your loved one. Enlist the help of a neighbor for an evening so you can get away from the house. If you work during the day, hire a babysitter for an evening and be sure to take that time for yourself.

"As a private geriatric care manager for almost 20 years, I have often been asked, 'How can I balance caring for my loved one and my own family?' My answer is tailored to each family's specific situation," says Erica Karp, LCSW, CCM, president at Northshore ElderCare Management, Inc. in Evanston, Illinois. "However, there is a basic message behind all of them. It is similar to the advice given on an airplane when they say what to do if the oxygen masks deploy: put your own mask on first and then assist the dependent person traveling with you. The same goes for caring for a relative in your home. You have to first make sure that you have a life and that you take care of your own survival needs. Then you will have the presence of mind to care for your relative."

Martin agrees. "You have to allow time for yourself," she says. "You have to be fueled before you can do anything for anyone else – it's the proverbial 'running on empty.'"

Don't Do it Alone

Caregiving can be an emotional roller-coaster. For parents who are still in the throes of raising young children, the added stress of caring for an elderly loved one can

be overwhelming. The feelings of love and commitment to your loved one drive you to *want* to do everything you can to ensure they are comfortable and well taken care of, but the demands on your time can often become too much for one person to carry. It's easy to slip into feelings of guilt – at not doing everything for everyone – and of resentment towards those you love the most. This can lead to burn out, stress and even depression – if you don't have a plan.

One of the first things you should do is to understand the expectations and to be sure that everyone in your family understands them. Everyone needs to know, both young and old, what challenges you face as a caregiver. If your loved one is in a limited capacity, then your immediate family needs to know what to expect as far as caring for them in your home. Don't be afraid to be honest with your children. Invariably, children understand more than we, as parents, think they do. They know that things are different; they just want to know how it will affect them.

Often, the best way to keep things smooth is to enlist your children's help whenever feasible. Have them read to your loved one, or keep them company while they are watching their favorite show. Teach them how to bring a meal to them. There's a lot that kids can do to help, and they're often eager. This will lessen any resentment they might have towards their elder relative.

"It's a good idea to involve the whole family, without it seeming like caregiving," says Martin. "Of course, it will depend on the severity of the ailment and the limitations."

Martin also suggests that caregivers and their families enlist in support groups to help understand the expectations and as a source of ideas for successfully balancing it all. "Join a group where people are in the same position as you," she says. "The payoff is enormous."

The Internet is a good resource for families who are caring for loved ones. There is a vast number of support groups you can visit without even having to leave the house. Log on to one and find out what others are doing to manage family and caring for a loved one. Share ideas.

Organize the day to include time for everyone – especially for yourself. If you're not taking care of yourself first, everyone around you will ultimately suffer. ... enlist your children's help whenever feasible.

Timely Tip:

Sleep is very important for caregivers and elderly alike. You can minimize the problem of insomnia and increase the likelihood of good sleep if you:

- Check medications to see if they have side effects that affect sleep
- Restrict eating and drinking before bedtime to avoid having to get up to use the bathroom in the night
- Set a positive sleep pattern by setting a routine bedtime
- Limit smoking as it can hamper breathing at bedtime
- Go for walks and other daily exercise outings

Caring for Your Family and an Aging Loved One

Continued from Page 7

If you have older children, they can be a great support for you. Older children can run errands, keep the younger children occupied

Timely Tip:

Grocery shopping can be an ordeal for the elderly, not only getting to the store and actually shopping, but getting the groceries home when finished. Ask the neighborhood grocery store near your elderly loved one whether they offer home delivery. Alternatively, you can order groceries online; these services include delivery.

Offer support. Seek advice. It's all there at the click of a mouse. (The website of this publication, www.caregivershome.com, has such a facility in its Community section.)

Seek others in your neighborhood who are in the same position and discuss ways to share responsibilities. Maybe you could pick up all the prescriptions this week and your friend can do it the next. Car pool with your neighbor's kids – this gives you extra time to care for the needs of your loved one. But have a clear plan.

If you have older children, they can be a great support for you. Delegate. Explain to your family that as a family, you take care of each other. Older children can run errands, keep the younger children occupied by playing a game with them or just talking with the elder family member. It's often the little things that matter most.

By involving the family, you are communi-

cating to them that this is something you all need to do together, as a family. There will be times when resentment will flare, but with a strong support system in each other, it will pass. Keep the lines of communication open and be sure to listen to each other. Children need to know that their mother or father is still there for them, even though life may be busier than it has been.

Caring for an aging loved one, and trying to manage your own home and family, can be a daunting task. However, with a little organization, a lot of communication and a willingness to reach out to your community for resources, you will find that "balance" is within your reach.

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The Caregiver's Home Companion

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Upcoming in February

- New Medicare regulations offer the elderly a government-sanctioned discount drug program card for the first time. What does it mean and how will it work?
- Caregivers have spent a generation coaxing their children to brush and floss twice daily. Now it's their turn to oversee dental hygiene for their parents.
- How do children respond to aging and illnesses of their grandparents, especially those with hard-to-explain diseases like Alzheimer's. A caregiver's guide to helping kids cope with these changes.
- Talking with your elderly loved one's doctor — how to effectively get the answers you need and deserve.