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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

Stop Pushing My Buttons!

How to Cope When Caring for a Difficult Parent

By **Melissa A. Goodwin**

Elizabeth, a busy working mother of three from Phoenix, helped her ailing 85-year-old mother with grocery shopping, meal preparation, and transportation. Eventually, Elizabeth learned of a volunteer caregiving program that helps with shopping and transportation, so she signed up her mother for services.

But after a few weeks, Elizabeth's mother was still calling her for help, saying that no one from the program had been able to provide assistance. Elizabeth called the director of the program and learned that her mother had actually refused their assistance, telling them that her daughter Elizabeth would take care of everything!

When confronted, Elizabeth's mother said, "It's embarrassing to have a stranger drive me when I have a daughter living so close by. I'm your mother; you should want to help me!" Elizabeth had reached the end of her patience. Of course she wanted to help her mother, and she did as much as she could, but she was jeopardiz-

ing her job with all the time off. Why couldn't her mother understand that Elizabeth just couldn't do everything? She seemed to know just what buttons to push to make her feel guilty.

No matter how close the relationship, parent-child dynamics

always exist. It's amazing how quickly old issues can arise—an offhand remark or a certain look from a parent can instantly make you feel like a child again. When the child becomes the parent's caregiver, those dynamics can become magnified. And, if the relationship has always been a difficult one, the caregiving situation can feel almost unbearable.

Parents fear the loss of control over their own lives and the sense of helplessness it brings. They may resent being dependent on their children for help, yet

afraid of not getting that help. The tug of war over roles and control can play out on a daily basis in the form of button-pushing behavior that ranges from needy, manipulative, and demanding to verbally and emotionally abusive. ▶



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"Parents know how to push your buttons because, hey, they sewed them on." –Camryn Manheim, Actress

How to Cope When Caring for a Difficult Parent *Continued from page 1*

So, how can you manage a "button-pushing parent" without losing your temper or your sanity? Consider the following:

Change your response: It helps to accept that you can't change another person, especially at an advanced age. But you can change your reaction to your parent's behavior. Try responding to the situation itself, not what the person says or does. Mom or Dad is just trying to get their way and will say anything to get it, even things that hurt your feelings. Instead of getting hurt or upset, calmly stick to your guns. It might even help to pretend that it is someone else's parent, so you don't personalize what they say as much.

When your parent is pushing your buttons to get their way, stop trying to bend over backwards to please. Accept that no matter what you do, it may never be enough in your parent's eyes. You know that it is enough, so be kind to yourself and try to let go of any guilt.

Have compassion for yourself: While your parent has a right to his or her emotions, so do you! You are human and sometimes will get angry, frustrated, and fed-up. Don't beat up on yourself for having these feelings. It's all right for you to know and accept that you are doing the best you can, even if your loved one can't or won't acknowledge it.

Set Limits: It is essential to set boundaries and then stick with them. Let your parent know you aren't available 100% of the time. Tell them how often you will help, and make it clear that this is the absolute limit of your availability. Then stick to it.

Tell, don't ask: I know it sounds tough, but tell your parent how the situation will be handled and then just do it.

Elizabeth told her mother that she had to accept the assistance of the volunteers. Her mother didn't like it at first, but after only a few weeks, she couldn't say enough wonderful things about all her new friends from the volun-

teer program. People resist change, but if you stick to your guns, it's likely that your loved one will eventually accept the new situation.

Do what you need to do to make things easy on yourself. If necessary, blame a decision on the parent's doctor. One burned out caregiver asked her dad's doctor to write a prescription that said that her father needed to attend adult day care three times a week, and the doctor did!

Get professional help: If your parent is particularly difficult, eldercare consultants can help. These professionals are trained in eldercare issues and in dealing with the elderly. Often parents who will not listen to their children will listen more readily to an "expert."

Because the consultant is not personally attached to the situation, he or she can more easily deal with the loved one's emotions. The consultant can play the "bad guy" by explaining decisions to the parent and taking the pressure and "blame" away from you.

Locate and use your support systems: Churches, nursing homes, and senior centers may offer programs that can help you and your loved one. Look for support groups that help you cope with your parent's behavior and programs that can give you some respite from the situation. Volunteer programs such as the one Elizabeth uses are found all across the country, and can be located on the Faith in Action website at www.fiavolunteers.org.

Informal support systems include your friends and family. Make sure all family members are helping in some way, even if it's just a short visit or a weekly phone call. Talk to your friends about the situation, and share your stories. You'll be surprised at how funny the stories can sound when you tell them to a trusted friend. So, have a good laugh sharing tales of parental button-pushing and you'll quickly find out that you are not alone! ■

RESOURCES

Family Caregiver Alliance, www.caregiver.org

The 36-Hour Day, Revised Edition, Nancy L. Mace, M.A. and Peter V. Rabins, M.D., M.P.H. The John Hopkins University Press, Baltimore, 1991

Faith in Action, www.fiavolunteers.org

National Association of Geriatric Care Managers, (520) 881-8008 or www.caremanager.org

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Traveling a Lonely Road

Caregiving and the Only Child

By Ursula Furi-Perry

Caregiving can be a lonely job for anyone, but for those from single-child families who are caring for their parents, the job can be even tougher. Without siblings, elder-caregivers may have less chance to share responsibilities with others. They may have to make important, sometimes life-changing decisions alone, and they may have few chances to discuss caregiving with others who are familiar with the loved one.

“The immediate reaction is ‘woe is me; how am I going to do this alone?’” says Gail Mitchell, founder and president of the National Organization for Empowering Caregivers.

For many only children, the degree of responsibility for the loved one may be overwhelming, adds Jeri Hepworth, Ph.D., medical family therapy professor and Vice Chair of Family Medicine at the University of Connecticut School of Medicine in Farmington, Connecticut. Obviously, caregiving responsibilities are seldom shared with others when there’s only one child, and “often, the decisions that have to be made are difficult for one person to make alone,” Hepworth says. “The sense of consensus isn’t available to the only child.”

The stress on the caregiver’s own family may also be greater when no siblings are involved. “It’s hard to explain to your partner the degree of responsibility that only children feel in these situations,” says Hepworth. Additionally, family tensions may be exacerbated if the caregiver already has a rocky relationship with their parents, such as in situations involving past abuse, Mitchell points out.

Suzanne Modigliani, an only child, cared for both of her parents—a father



with dementia and a mother with physical difficulties. She describes the process as overwhelming, “emotionally difficult and time-consuming.” She found her rock in the support system of her broader family, says Modigliani, now a geriatric care manager in Brookline, Massachusetts.

In fact, experts agree that finding support—both caregiving help and emotional encouragement—is one of the most essential considerations for caregivers who are only children. Family members who are familiar with the loved one, support groups both on- and off-line, and profes-

sional therapists can provide invaluable emotional support in the wake of only-child caregiving difficulties and stress.

For physical help with the caregiving process, consider hiring a qualified professional, such as a home health aide, to help you handle everyday tasks. A geriatric care manager can also help oversee care, including finding resources in the community, assessing your loved one’s needs, providing reassurance to the caregiver, and helping solve common caregiving problems.

Additionally, becoming totally informed and educated about the loved one’s health, needs and condition are especially important for only children who often bear sole responsibility for decisions about the loved one’s health.

Caregivers without siblings must also set boundaries, says Mitchell, carefully examining the balance between their caregiving responsibilities and the rest of their lives. “Whether they’re thrown into the situation or have chosen to move into it slowly...it’s important to stay balanced,” says Mitchell. Achieving balance may require communicating one’s limits, needs and feelings to the loved ones and others, as well as setting clear boundaries as to how much the only-child caregiver will—or can—take on.

Finally, Mitchell reminds that it is perfectly okay to say no. You don’t absolutely have to care for your loved one just because there are no other children to take on caregiving duties; check out other appropriate options, including home health aides, assisted living facilities, or hospice care. “(Caregiving) is often a marathon, not sprints,” says Hepworth, adding that caregivers without siblings must think carefully about what they can and cannot do as part of their caregiv-

ONLY-CHILD CAREGIVING CHECKLIST

If you are an only child caring for your parents:

- ✓ Don’t do it alone: get physical and emotional support.
- ✓ Consider other caregiving options to help take some of the load off.
- ✓ Strive for balance between your caregiving responsibilities and the rest of your life.
- ✓ Set boundaries—no caregiver is an island.
- ✓ Communicate your needs, thoughts and frustrations to your loved one and others.

Ursula Furi-Perry is a writer based in Haverhill, Massachusetts. She can be reached at furiperry@verizon.net.

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When Mom Moves In

Surviving Under the Same Roof

By Kelly D. Morris

You did it when you were a kid, right? So how hard can it be?

"It was an easy decision for us," says Ella Sharpe. Her father moved in with Ella and her husband in Colrein, Ohio, after his wife died.

Ella's husband Bill agrees. "We'd always been a close family, and we had plenty of room."

It's not always so easy, though.

"It's a challenge for us," Jean Donovan of Milford, Ohio, says. "I was used to being so independent. And my daughter, I know she means well, but she always wants to tell me what to do and how to do it."

Jean's daughter Janet agrees that things can get difficult at times. "Mom can be so stubborn," she says. "I'm just trying to help and she gets offended and thinks I'm treating her like a child."

Kerry Dioni, a home health aide in Green Hills, Ohio, offers this objective view: "It really depends on the family dynamics. Sometimes it works out great, other times it can be a disaster. Families need to think it through very carefully beforehand."

Kerry recommends considering the following when making a decision about whether to have your elderly loved one move in:

- **Do you have an extra room in the house?** Having Dad sleep on the couch just isn't going to work.
- **Is your house accessible?** For instance, if Mom uses a wheelchair, are doorways wide enough to accommodate the chair?

- **Are you able to meet their personal care needs?** If they need around-the-clock care and you work full-time, that's going to be a problem.
- **What will you do with their possessions?** It will be hard for them to part with many of their belongings, but everything is not going to fit into your house.
- **Do you get along well?** I mean, *really* get along well? And how well do you communicate?
- **How do your spouse and children feel about it?**
- **How does your parent feel about it?**

Take your time answering these questions before making a final decision.

Stressors Are Everywhere

Having an elderly parent move in with you can be stressful for everyone involved.

For the elderly parent, it's hard to give up some independence. They may feel as if they have become a burden. They will be losing their home, where they may have lived for many years. They probably won't be able to move all of their possessions to your home. They will have less privacy. If you have children of



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your own, Mom or Dad will have to get used to living with kids again.

In turn, you may feel you're losing some of your privacy—because you are. You may worry about the extra work required to care for your parents. Mom or Dad may interfere with your children. They may annoy you at times. You may start to feel you're being treated like a kid again yourself.

Don't forget that it will affect your spouse and your own children, as well. It's a big adjustment for everyone involved.

Talk things out as much as possible before making the move. Agree on some ground rules. Be willing to compromise. There are ways to make it work.

Tips for Success

Try these tips to smooth the way:

- **Have regular "family meetings."** Include everyone in the household, young and old. Talk about how things are going. Again, be willing to compromise. Be creative when coming up with solutions to problems.
- **Allow Dad to bring as much of his "stuff" as possible.** Being surrounded by familiar items will make him much more comfortable. Especially if he has Alzheimer's disease or some other form of dementia, having his own things will help keep him oriented.
- **Let Mom help when she can.** Being productive will go a long way toward helping her accept the new living situation. It can also lighten your load.
- **Give everybody some privacy.** You all need time alone.
- **Allow Dad to be as independent as possible.** Don't do for him things he can do himself, and don't be bossy.
- **Make it clear who the parent is.** If you have children of your own, Mom should not interfere with how you raise them. For example, she shouldn't give them cookies right before dinner when you've already said no. She shouldn't let them go outside when you've told them they had to finish their homework first.
- **Get help.** If Mom or Dad requires a lot of care, get help. Ask siblings to help out and consider some sort of home health services. There are a number of services designed to help the elderly stay at home, and that includes staying in your home, if they can no longer manage on their own.

What's Best for All?

Moving Mom in is not always the best decision.

"It was a gut-wrenching experience, having to make that decision," says Sandi Kivkovich of Clifton, Ohio. Both of her elderly parents require around-the-clock care. "They have so many problems that are very scary. I just can't meet all their needs."

If you work full-time and your parents need full-time care, moving them in may not be an option. You might be able to make it work, though, if you can get some assistance.

Another issue may be your house itself. You may not have room for another person. Mom might use a wheelchair, while your home may have lots of stairs. It's important to consider the practical aspects of the decision.

In some cases, families just can't get along when they live together. You may love your parents, but find it impossible to live with them. You'd both be miserable. You both need to be honest about that if it's the case.

Remember, choosing other living arrangements for your elderly parents is not a reflection of your love for them. Each family has to do what's best for them. ■

WHERE TO GET HELP

When it comes to coping generationally under the same roof, look for the Area Agency on Aging in your local telephone book or contact the National Association of Area Agencies on Aging by calling **202-872-0888** or visiting their website at <http://www.n4a.org/>.

Through these groups, you can get a free assessment to find out what types of services your parents qualify for. Some things they might be eligible for include:

- meals on wheels
- home-making services
- help with personal care
- adult day care
- transportation to medical appointments

Caregiving and the Only Child

Continued from page 3

ing duties.

Despite the hardships, there are positives to the only child-parent caregiving scenario: in some ways, being an only child may even make caregiving easier. "The truth is that most people who have siblings are very lonely caregivers also," says Mitchell. In many families, one sibling ends up doing all of the caregiving anyway—and worse yet, the caregiver may be reprimanded by siblings for his or her choices, all the while receiving little help from the siblings.

As the sole caregiver, only children may have more control over caregiving decisions, Mitchell explains, and won't have to face criticism from siblings. When Modigliani helped clean out her parents' house, her mother commented that since she didn't have a sister, at least there wouldn't be any fighting over the dishes.

What's more, being an only child may make it easier to move the parents into the caregiver's home or closer to the caregiver, says Hepworth. "You don't have the competing loyalties to other siblings," Hepworth explains. "Parents are more likely to stay in their home longer than they should (if they have more than one child) because the parents don't want to do the choosing."

Caregiving may also bring the solo caregiver and loved one closer together, and Hepworth says only children are more likely to be close with their parents. Caregiving can also mean discovering pertinent information about the parents' well-being: Modigliani says it wasn't until she moved her father into her home that she discovered the true extent of his dementia.

While the job may be much tougher when there are no siblings to help, only children caring for their parents can manage with careful planning, clear boundaries, and plenty of outside support. ■

RESOURCES

The National Organization for Empowering Caregivers, www.nofec.org

National Association of Professional Geriatric Care Managers, www.caremanager.org

Only Child Online Magazine, www.onlychild.com



Paget's Disease

Boning Up on a Painful Bone Condition

By Sharon Palmer

It's a dangerous and painful proposition for our elderly: Bones bend or break with alarming results, including a host of debilitating and sometimes fatal unrelated conditions. As conditions worsen, fear wells up in aging men and women who wonder whether they're safe on their feet.

What's the cause of this physically and emotionally destructive life stage for some of our elderly? Paget's disease of the bone, named after an English doctor who first described it in 1876, and it's a lot more common than you might think. And, sadly, there currently is no cure.

Even though you probably haven't heard much about this chronic disease of the skeleton, it behooves caregivers to bone up on it, since it occurs in nearly 4% of the population over age 50, representing about 1 million older people in the United States alone.

How does Paget's disease wreak havoc on the bones? In normal bone, a process called remodeling routinely takes place, in which bone is absorbed and then reformed due to the normal wear and tear on the skeleton. But in Paget's disease, the bone breaks down more quickly, and when it grows again, it is softer.

The resulting condition can cause bones to bend or break more easily, become more painful, produce an increased blood supply to the bone, cause the bone to become shorter if it bends, or

promote the bone to grow larger than before. Affected bones are usually located in the skull, hip, pelvis, legs, and back. And if untreated, Paget's disease can lead to osteoarthritis, kidney stones, and heart disease.

The researchers don't fully understand what causes the disease. Some studies have shown that more than 30% of sufferers have family members with Paget's and that it is more frequent in those of Northern European descent, indicating that it might have a genetic link. It also occurs slightly more often in men than women. While unproven, some scientists think its cause may be related to a virus.

Easing Paget's Burden

If you suspect your loved one is suffering from Paget's disease, the first thing to do is schedule an appointment with their physician, who may want to perform an examination, blood tests, bone scans, or x-rays in order to make a diagnosis.

The treatment for Paget's disease includes reducing the rate of bone loss and managing the pain. Bisphosphonates and calcitonin are medications often used to help promote normal bone in Paget's disease conditions, and acetaminophen is often used to help control pain. Non-steroidal anti-inflammatory drugs may be used for swelling and pain, as well.

Your doctor may also refer your loved one to a specialist, such as a rheumatologist or endocrinologist for further evalua-

tion. Sometimes, if significant damage has progressed, surgical intervention may be indicated.

Focus on Diet, Exercise

The proper diet can help manage Paget's disease. In part, achieving and maintaining a healthy weight can avoid putting extra strain on the bones. It is also important to maintain a good intake of calcium, a mineral used to build bones. In general,



PAGET'S WARNING SIGNS

While Paget's disease of bone is quite common, it also is a slow-progressing disease among the elderly, so it can be easy for caregivers to miss these red flags in their loved one's daily life:

- Affected area may feel very warm.
- Pain over the bone.
- Feeling of fatigue.
- Bone shape may change to be bent or bowed.
- In the skull, the head can enlarge or hearing difficulties can occur.
- Easily broken bones.



if one suffers from Paget's disease, it is recommended they receive 1000–1500 mg of calcium, adequate sunshine, and at least 400 units of vitamin D daily. Make sure your loved one drinks plenty of water or fluids (at least six glasses per day) to maintain a good calcium balance, and bone up on calcium in such food sources as dairy products, cheese, salmon, sardines, almonds, dark green leafy vegetables, and fortified orange juice. Discuss calcium and vitamin D supplements with your healthcare provider.

An exercise plan can also help ease the stress of Paget's in many ways. Exercise can help decrease stiffness, maximize flexibility, and help keep weight under control, thus putting less strain on the bones. However, the wrong kind of exercise can put one at risk of breaking bones, so it's very important to speak with your healthcare provider about starting an exercise program best suited for your loved one. A physical therapist can also help plan an optimal exercise program.

Treat the Body Kindly

Remember to treat the body with kid gloves by protecting it from further strain. Pace your loved one's activities between repeated or heavier tasks with lighter ones and more frequent breaks. Position the body in order to transfer the stress off vulnerable bones and joints and onto larger, stronger ones. And encourage your loved one to not resist reliance on helpful devices

to ease the load, such as canes, push carts, shower seats, and reaching aids.

Don't forget that developing good relaxation techniques can further take the stress off the mind and body.

Turn to hot and cold applications to help temporarily manage discomfort. Applying heat, such as a hot pad or hot shower, can help to relax painful muscles and reduce pain and stiffness. Applying an ice pack can help lessen soreness and swelling.

In the end, Paget's is very painful. It is important to remember that if your loved one suffers from the disease, do all you can to learn more about easing the pain. ■

RESOURCES

Check out these resources to learn more about Paget's Disease:

NIH Osteoporosis and Related Bone Diseases—National Resource Center

tel: 1-800-624-2663

web: www.niam.nih.gov/bone

National Institute of Arthritis and Musculoskeletal and Skin Diseases

tel: 301-495-4484 or 1-877-22-NIAMS

web: www.niams.nih.gov

National Library of Medicine

tel: 1-800-272-4787; web: www.nlm.nih.gov

The Paget Foundation for Paget's Disease of Bone and Related Disorders

tel: 1-800-237-2438; web: www.paget.org

Sharon Palmer is a registered dietician with 16 years experience managing healthcare food and nutrition departments. Her career has included clinical nutritional care for a broad spectrum of patients, from eating disorders to elderly. She also has managed the food and environmental services departments in several acute care hospitals. Ms. Palmer lives in Southern California and can be reached at spalmer952@earthlink.net.

COMING UP IN MARCH

- Mom and Dad are breaking up? At their age? As over-65 divorce gains favor as a financial safety mechanism, a look at options for caregivers in guiding seniors to safe harbors.
- A geriatric care manager can be a family elder-caregiver's best ally. Who are GCMs and what can they do for you?
- A look at strategies to help our elderly continue to live independently in the face of illness or disability.
- You're never too old for pain-relieving foot surgery. Keeping loved ones on their feet—mobile, happy and “worthwhile.”

Transport Chairs: Keeping Mom Mobile—Without Breaking Your Back

By Molly Shomer

Are you reluctant to take your elder out because walking is a slow and exhausting process that wears out your senior and drives your own patience into the ground? Or is lifting a heavy wheelchair in and out of your car trunk giving you back problems of your own—if you can lift it at all?

Taking someone with mobility problems out for recreation is often such a debilitating chore that we find ourselves not going out together frequently. This is a sad state of affairs for everyone.

Our elders end up stuck in the house except for unavoidable medical appointments. This can lead to boredom, depression and a feeling of worthlessness. We caregivers end up feeling guilty that we avoid going out because it's literally a pain.

There is a solution. Like just about everything, it involves spending a little money, but the expense will be far less than the cost of a chiropractor or antide-

pressants—or both—and the rewards can be huge.

The answer is a transport wheelchair, a lightweight (some are less than 20 pounds) chair that folds easily and is no great chore to lift into a car trunk. They are narrower than a standard wheelchair, so they fit comfortably through most doors. You can fold, lift and store most travel wheelchairs without having to remove the footrests, so it's a quick and easy job to get up and go.

Even people who don't normally use a wheelchair find that a travel chair makes outings and special events more pleasurable and less exhausting.

Transport wheelchairs start at around \$150, although you can sometimes find special deals for less. Because they aren't designed to be used as a primary wheelchair, and they are designed primarily for use outside the home, Medicare doesn't cover transport chairs.

Even transport wheelchairs need to be properly sized for the user, so I don't rec-

ommend that you purchase a chair without having the person who will be using it actually sit in the model you will be purchasing. For this reason, unless you have already sampled transport chairs and have selected the size and model you need, I don't recommend ordering a chair from a catalog or website.

However, there are many reputable wheelchair vendors who do offer travel chairs on the internet at prices below what you might find at your local retailer. Visit several web sites for an idea of what's available for your needs and in your price range. Then visit a local retailer to try out chairs and compare prices. You can then decide whether you prefer to buy locally or order from a more distant source. ■

Molly Shomer, MSSW, LMSW, is a family caregiving specialist and licensed geriatric care manager. She authored The Insider's Guide to Assisted Living, her website is www.elder-careteam.com, and she can be reached at molly@elder-careteam.com.

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