

The Caregiver's Home Companion

"Helping Those Who Help Others"

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This Month Online

We're pleased to announce a birth in our publishing family – a new weekly emailed newsletter that is yours – free – as an added value for being a subscriber to *The Caregiver's Home Companion*.

The Caregiver's Hotline is a very timely, complementary addition to the *Home Companion*. Whereas this newsletter is filled with valuable caregiver advice, tips and how-to features, you'll find *The Caregiver's Hotline* keeping you informed and up-to-date on important news developments for caregivers and the elderly.

No matter where the news occurs, *The Caregiver's Hotline* will bring it to you – from Medicare developments in Washington to regulatory news from the states, from promising drug research to FDA approvals. And much more!

If you did not submit your email address when you subscribed to this newsletter, please visit our website and register for your free subscription to *The Caregiver's Hotline*. Sign up at <http://www.caregivershome.com/newsletter/newnews.cfm> and start receiving the Hotline in your e-mailbox every week.

Caregiver Respite

Recognizing and Realizing the Rest Every Caregiver Needs

By Amelia Fletcher



The half-full coffee cup sat on the kitchen counter getting cold as Pat stepped back into the bedroom to get towels and other supplies ready. This is bath time for her bedridden mother. She sighs and knows that she might get another coffee break in an hour or so, if she's lucky.

Pat is not alone in this pattern, and like Pat, nearly 25 million family caregivers in America are stretching themselves thinly, balancing children, spouse, an older loved one, and all the tasks that need to be done for a household and family. As a caregiver, Pat could use a rest – or respite — from all the demands her life has placed on her now for several years.

The term "caregiver respite" has a standard definition within the healthcare community: it is a short and temporary break from caregiving duties and a break from the routine. That sounds

simple enough, but caregivers develop habits with their time that don't allow for personal relaxation and rest.

Lance Robertson, director of Replenishing the Caregiver, an outreach program at Oklahoma State University, urges, "Take any amount of time you can away from the caregiving situation. Long periods of time might be hard for families to manage, but even an hour away to do some shopping or just to sit and clean up your desk without interruption can be valuable and bring you back to your caregiving duties refreshed."

His program, like many university-guided programs developing all across the country, offers respite care so family members may attend training courses, many of which are free. Their goals are to rejuvenate and support caregivers so they don't experience burn-out and isolation. Caregivers often act like the

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Caregiving and the Only Child

You're Not Alone When You Muster Your Own 'Team Approach' to Caregiving

By Gwen Morrison



PHOTOCOLLAGEBYDAVIDROBBINS

If three out of every four family caregivers polled recently said they felt most anxious in their role when confronted with a lack of consistent help from other family members, how must an only child caring for an elderly mother or father feel? Where do they turn? What unique obstacles do they face when caring for an elderly parent?

Despite the finding in a nationwide survey by the National Family Caregiver's Association, there is no comparable lonely or anxious feeling in caregiving as having no siblings to help, no matter how little or much, in caring for an aging parent.

In families where there is only one child to care for an elderly parent, there is a unique challenge, to say the least. You alone are the one who is ultimately responsible for caring for your parent and must therefore make decisions that guide your parent's last years and shoulder the load without benefit of bouncing feelings and questions off a sibling you've known all your life.

As an only child, you don't have a sister to call to talk about the stress of caring for your parent while trying to maintain a healthy relationship with your spouse. As an only child, you don't have a brother to call on when you need someone to fly in and help your parents move into their retirement home. As an only child there are times when you may feel very alone when it comes to caring for your aging parent. You are the one who must be there, no matter what. You feel the ultimate responsibility of giving back to your parents for all the years of care they provided you. And, it can be an overwhelming responsibility to carry all on your own – I mean all on your own.

Don't Go It Alone

The truth is that no one can or needs to do it alone. Even though your family unit doesn't include siblings, there are extended family members you can call on – aunts, uncles, cousins, nieces and nephews. Help can also be found in your community, within your parent's circle of friends, and with professionals. It is not realistic to believe you can do it on your own.

Involving extended family and friends allows you time to recharge, and it also gives them the sense that they are important to your small family. It also gives people a way to extend their own love for your aging

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Redefining Normalcy

Help for Grieving Caregivers Dealing With a Great Sense of Loss

By Ursula Furi-Perry



DAVID ROBBINS PHOTO

It's difficult to rearrange one's entire life around providing care for a loved one. It's even harder to attempt to move on after the loved one's passing.

Not only is the caregiver losing someone dear and mourning their loss, they are suddenly thrust into a vacuum as the high-wire act of balancing life and caregiving for the past several months or years takes another, final and sudden turn. Just how does one return to normalcy after so much time devoted to caring for a loved one?

First of all, be ready to redefine normalcy, says Jane V. Bissler, Ph.D., LPCC, a noted grief counselor. "The work is not to return to normalcy, it is to create a new normal," Bissler explains. "It takes a lot of time and a lot of hard work to assimilate (caretakers') loss into their lives. When that assimilation is complete, (if ever)...life will never be the same again."

Russell Friedman, executive director of The Grief Recovery Institute Educational Foundation, agrees. "Normalcy is the ability to develop a new norm in light of the changes that are both explicit and implicit following the death of a loved one. Since things can never be the way they were before, it is important to establish that new habits and actions must replace old ones, in light of the fact that someone important to you is no longer physically alive."

The adjustment process may be tougher for caregivers than others. In addition to the caregiver's grief and loss, a large part of their daily routine changes upon the death of a loved one. "Often caregivers do not know what identity they have or even want after their loved one dies," says Bissler. "They also usually have more time on their hands, and although for some, this time can mean freedom, many caregivers feel guilty that they can now do things that they enjoy."

It's important to work through that guilt using activity and productivity. Friedman advises caregivers who have experienced loss to "retake a productive place in their lives, even though their lives have been massively affected by the death of a loved one."

Although the days of caring for the loved one will never resume, they can be replaced with other productive and pleasurable activities. Caregivers may try volunteering their time to take care of elderly or animals in the community. It may also help grieving caregivers to retain some of the familiar daily habits to which they had become accustomed — for example, if the caregiver took morning walks with their loved one, continuing to take the walks with an understanding friend may ease the grieving process.

It's important to grieve in a healthy way, allowing yourself to remember happy memories.

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Timely Tip:

You can help your elderly loved one preserve dignity and independence by encouraging them to bathe or shower themselves – but not without proper caregiver preparation. Be sure to securely install handles or grab bars in the tub area to provide stability. Don't rely on wobbly towel racks. Also be sure the area just outside the tub or shower stall has a rubber mat suctioned to the floor to avoid slipping. Naturally, one is needed inside the tub too. If the mat is thin enough, walkers or wheelchairs can be used right up to the tub entrance.

Help for Grieving Caregivers Dealing With a Great Sense of Loss

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Since the physical ending of relationships is so powerful, grievers find themselves with sometimes gruesome pictures etched into their memories. It does not do justice to a long-term relationship

Timely Tip:

With age and infirmity, the elderly can have a very difficult time getting into and out of their favorite chair. Some ways to help them: place a portable pillow atop the seat surface so they sit higher and can rise more easily. Or consider a mechanical "up-lift" device that installs on the existing chair and gently supports the person as they rise. The device senses that they are getting up because of reduced pressure on the seat.

Friedman recommends that caregivers "remember their loved ones the way they knew them in life rather than in death. Too often, an accident, a dreaded disease or some form of tragedy has altered the way people look when they die. Since the physical ending of relationships is so powerful, grievers find themselves with sometimes gruesome pictures etched into their memories. It does not do justice to a long-term relationship to have it frozen in one last horrible picture."

This will prevent wonderful memories from turning sour. It may be a good idea to put together a memory book or corner of a room in honor of your loved one, creating a place of happy remembrance for the grieving caregiver.

It is equally essential that caregivers confront an imminent death before it actually happens. Stay "in the moment" with the loved one, Friedman advises, and be sure to talk openly about what is forthcoming. Though death is extremely difficult to prepare for, experts advise caregivers not to lose focus of the fact that death is inevitable. "Though denial is primarily associated with the dying person, whose mind refuses to accept the diagnosis of a terminal condition, it is not uncommon for those who are emotionally attached to the dying person to share the difficulty of believing what is going to happen," says Friedman.

Bissler agrees: "It's hard to deny a death when you are making arrangements, fielding phone calls, answering the door, standing at the calling hours, attending the funeral, and writing thank you notes. People often suffer greatly if they have denied the death while it was hap-



PHOTOCOLLAGEBYDAVIDROBBINS

pening." It may be helpful for caregivers to have an outlet away from the loved one, such as a neutral person who will listen or an outside activity that will help the caregiver through this rough time.

Finally, it's important that caregivers seek help during the adjustment process. Don't grieve alone, says Bissler. "I often (ask) my clients, when they say they should be able to do this on their own, if they taught themselves to drive. Most of them say no. I then tell them that they were riding

in a car for 16 years, (yet) still didn't know how to drive well enough to teach themselves. Now, they are faced with a situation for which nothing in their lives prepared them, but they expect to know how to deal with it."

Some resources that may be helpful to caregivers are clergy or the staff at hospitals, hospices and funeral homes, many of whom will graciously refer caregivers to support groups and other sources of help in this situation. "Family members and friends who have not experienced a like loss are often not the most helpful, although they may want to be," cautions Bissler. "Bereaved caregivers are well advised to seek those who have had like deaths and network with them. They are the ones who truly understand."

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“How I Cope”

Under One Roof: The Caregiver’s Version of ‘Tag! You’re It!’

By Karen Luna Ray

Suddenly the shoe is on the other foot and it isn’t a comfortable fit. You have become the caregiver, your parent the dependant.

Juggling care giving for an elderly person, as well as tending to your children and spouse can easily become more than you bargained for. A delight one day, it can become a great source of inconvenience the next.

In my case, my mother-in-law became terminally ill and was gone from this world within four months. Left behind were her husband, who suffers from the advanced stages of emphysema, and her own elderly mother, both of whom she had taken care of for years. It was total chaos.

One day my husband and I had our own life with our two small children in a normal household. The next, after learning of my mother-in-law’s illness, we had three more people emotionally and physically dependant on us.

After trying to manage two households, in addition to making daily 50-mile trips for treatment of my mother-in-law, we gave up the rental home we were living in and moved into my in-law’s home. It was a hard decision, but we felt it a necessary one in order to help out and make it easier on us at the same time. Or so we felt.

During the weeks following her death, not only were we still trying to sort through our own belongings, we had to pack all of Grandma’s belongings for removal to her son’s home. My father-in-law decided he preferred another bedroom, so with hers, his and ours, we were in a constant game of musical furniture.

In its way, all this activity helped us through the emotional stress of giving up one who had been such a vital part of all our lives, but at the same time made its mark on us physically in the form of exhaustion.

We finally settled into a routine which works well for us for the most part. Although at times it is difficult to give my children as much of my

attention as they demand, I believe the values they gain from having their grandfather in the home outweigh the disadvantages.

Since my children are quite small, we installed a door to the room that serves as the entrance to my father-in-law’s portion of the house. The children know to knock before entering and that it is not their play area. This allows him needed privacy, as well as allowing us privacy as a family. If he has visitors, they can enter his portion of the house without coming into our living quarters, and vice versa.

We were then faced with the dilemma of being able to hear him if he called. Moving a monitor into his room proved to be a mistake. It was tantamount to having the entire family in the bed with us, what with the tick-tock of his clock and the coughing and snoring.

Finally, we hit upon the idea of a portable doorbell. It allows him to ring when he needs something and is very small so he can take it with him to the bathroom or wherever else he might wander.

After the first few weeks of showing his visitors how quickly I could get there when he rang, the newness finally wore off and he isn’t as apt to abuse the privilege of being waited on hand and foot. Now we know that when he rings it may well be an emergency, so our house rule is to drop whatever we are doing and go immediately to check on him. That also gives him an added sense of security, knowing someone will come quickly should he need help.

My pet peeve is that my father-in-law refuses to come to the table to eat meals with the family. It makes my job harder trying to deal with two small children at mealtime, in addition to preparing and delivering a tray for him, then going back to pick it up before cleaning the kitchen after meal time. On the other hand, he occasionally suggests if we want to pick up

...Moving a monitor into his room proved to be a mistake. It was tantamount to having the entire family in the bed with us, what with the tick-tock of his clock and the coughing and snoring.

Timely Tip:

Help your elderly loved one more easily use the toilet independently by placing toilet paper within easy reach. This can be done by attaching the paper holder within easy reach at the front of the toilet or by using a free-standing paper holder, again in front. Too often because of the way toilet paper holders are installed in houses – to the side or rear of the commode – a person must twist to reach the paper. And that can be very difficult or painful for your aging parent.

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Mustering Your Own 'Team Approach' to Caregiving

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It's important for only children to sit down with their parents and discuss the level of care that is required. As your parents age, they will still want to maintain control.

Timely Tip:

Use it or lose it. This saying applies to our elderly as well as the rest of us. Caregivers should strongly encourage, and even facilitate, movement and exercise as mobility increases elderly independence and decreases complications due to inactivity. Use exercises that put the major muscle groups through the full range of motion (ROM). If your elderly is unable to do ROM exercises independently, then you, as caregiver, must move their limbs through the ROM. Even the smallest efforts, if done consistently, will lead to greater elderly independence. Complications of immobility include muscle wasting, pneumonia constipation, edema (swelling), pressure ulcers, urinary problems, osteoporosis and blood clots.

parent. Reach out to the community for resources before your own health suffers. Don't wait until you are overwhelmed by the responsibilities of caregiving before seeking assistance.

Involve Your Parents

Caregivers are often surprised to hear that they are doing too much for their aging parent. If your parent is not mentally or physically disabled, there are ways in which they can help themselves. It's important for only children to sit down with their parents and discuss the level of care that is required.

As your parents age, they will still want to maintain control. As an only child, you must be clear in knowing what is expected of you, and relay to your aging parents what you are able to do for them.

When possible, formulate a plan that extends over a period of time – setting forth the concerns about healthcare, legal issues and housing issues. Being on the same page from the beginning is crucial, especially if you don't have a sibling to be your sounding board.

Enlist Your Immediate Family

You may be an only child with a family of your own. If you are married, with children, you may feel that caregiving has placed you on a tightrope. On one hand, as an only child, you can feel grateful to have the extra pair of hands in your spouse. On the other hand, you have to face the same struggles faced by other caregivers – namely, balancing it all.

While keeping your marriage and immediate family a priority, you will find that enlisting the help of your spouse and children will help you get specific things done. Involving your spouse and kids is also a great way to stay connected with each other. Children feel better about new situations when they are kept in the loop of what's going on. Don't underestimate what a young child can do to help your parent. Your 6-year-old can practice reading skills with Grandma and your teen-ager would likely be thrilled to

drive Grandpa to the store to run a few errands.

Pros and Cons

"There are pros and cons to caring for an aging adult as an only child," says Valerie VanBooven, RN, professional geriatric care manager and author of *Aging Answers* (LTC Expert Publications, 2003). "The pros are that you don't have to feel guilty about making a decision that the other siblings disagree with. There are fewer communication problems. Many times in a family with multiple siblings, one sibling is the primary caregiver/decision maker, and although the others are less involved, they sometimes criticize the decisions made by the sibling in charge."

On the "con" side of it, you don't have siblings to commiserate with when you are making key decisions for your parent. "My best tip for surviving caring for an aging parent as an only child is to surround yourself with professionals who can assist you," says VanBooven. "Have a team."

VanBooven suggests that only children who are caring for aging parents include a professional geriatric care manager, elder law attorney, and a certified senior advisor as a part of their team. "This is good advice even for a family with many siblings ... however, for the only child, getting the right advice from the right professionals is key," she says. "Make sure that all the bases are covered — quality care, legal documentation and financial matters."

VanBooven says caregivers who are only children need to make sure they take a break from the responsibilities every now and then. "Hire someone else to come in and provide care while you rest," she says. "This is called respite care. It is ultimately very important for caregivers to care for themselves in order to avoid burn out."

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

Recognizing and Realizing the Rest Every Caregiver Needs

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mythological Atlas: they bear the weight of the entire family on their shoulders and even if coaxed into putting their weight down for a bit, they are always quick to pick it back up.

Pat, reluctant to leave her mother, is typical of most caregivers. "It seems like Americans are very giving, and so they see it as a sign of weakness if they bring in hired help. They also fear that if they delegate some of their time and tasks away from their home and loved one, they will disappoint their families by not meeting their expectations of care," Robertson explains. "And every family has its own unique situation, but respite care is a gift of time for families to recharge their batteries and regain a feeling of normalcy."

Respite care comes in many forms. It can be as casual as a church volunteer or relative being willing to sit with a loved one for an afternoon, or as sophisticated as an out-of-home care provider with trained staff to keep a loved one overnight and the ability to meet detailed medical needs. There are also private duty providers, but for many families this can be too expensive.

However, Linda Lamberth of the Alabama Lifespan Respite Project suggests, "Many states have voucher plans. These vouchers access designated funds without attaching strings so that caregivers may hire or provide services appropriate for their situations.

"Also," she adds, "programs run by non-profit organizations may assess fees for services on a sliding scale and be income based." She also reminds, "Don't forget to check for eligibility for Medicaid waivers. Tap all the financial means you can find."

Too often families with community and religious ties don't realize they have ready access to respite resources. They may also be like Pat, who has had close friends and relatives offer help many times over, but has never accepted these offers. She doesn't realize that these informal respites can prove to be reliable and rewarding experiences for all parties involved. Learn to trust in their willingness to help and offer them specific ways they can help you and your family. Maybe they can prepare a meal each week or plan to be a sitter on the same day each week so you can plan an outing with your spouse or children.

Too often families with community and religious ties don't realize they have ready access to respite resources ...Maybe they can prepare a meal each week or plan to be a sitter

"Remember that our loved ones benefit from seeing different faces or different settings. They get bored just like we do with the same old thing day in and day out," reminds Lamberth, "so take advantage of those volunteers."

While not appropriate in all situations, the University of Utah's Gerontology Center has developed tapes for a video respite. The tapes, when used with people with moderate to advanced dementia, encourage a care recipient to watch and participate along with the video visitor on the screen. While the tapes play and have the attention of their loved one, a caregiver may have 20 to 50 minutes of respite – enough time for that cup of coffee waiting on the counter to be refilled and consumed hot!

Before any program is implemented or any care provider hired and brought in to work in your home, remember to act like an employer. Write down the things you need from a provider. Can the provider lift mom out of her chair or handle the physical and emotional challenges of your particular situation? Are they certified? Do they have references? Do they have a pleasing interaction with other family members and you? If you ask the important questions before you hire or put a program in place, you will be able to leave your precious person in their hands with an easier mind and truly have a time of respite.

Remember, families are forever growing and changing, and you sometimes need simply "at home" time to play in the backyard, paint a child's room, go to a son's graduation or granddaughter's dance recital without caregiving responsibilities.

Acknowledging that you need some time away is not being selfish. It is the beginning of your acceptance of the need for respite and recharging. By taking care of yourself and spending some time in respite, you give the gift of a happier and healthy person to your loved one.

Amelia Fletcher is a writer and family caregiver living in Gulf Shores, Alabama. She can be reached at kenboh@gultel.com

In the News

Communication is, as they say, a two-way street. And when it comes to communication with Alzheimer's patients, both of you may have a difficult time understanding the other. The Alzheimer's patient can have trouble processing what you say, and you may not follow what they say because they mix words or repeat words or phrases.

The Mayo Clinic offers these tips to improve communication:

Show interest by maintaining eye contact and staying close to your loved one.

Avoid distractions and noise that can interrupt concentration.

Talk in short sentences with simple words.

Don't interrupt or hurry an Alzheimer's response, even though it may take minutes for them to answer.

Finally, realize that the frustration with communication works both ways and is the result of your loved one's disease, not their attitude. Be patient.

The Caregiver's Version of "Tag! You're It!"

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Timely Tip:

What is the body's largest organ? If you said "skin," you'd be correct. Caregivers can use the elderly's skin condition as a rule of thumb to gauge health, even though dry skin typically afflicts the elderly. Keep your loved one's skin clean, using oil-based cleansers, and well lubricated, especially if they have lost mobility. Skin should be examined regularly for signs of pressure.

Whether you choose to have your dependant parent live in the home with you or in a nursing facility will, of course, depend largely on individual situations,

something "takeout," he will buy. In this way, he makes his contribution to our meals, as well as gives me a break from cooking.

Another problem is that of telephone privacy. When one is house-bound, or even worse – bedfast, boredom sets in and the phone becomes entertainment. It is most annoying for other members of the household to have someone listening in on their conversation, and short of being rude, the only way to handle this problem is to install a separate phone line. It may seem like a waste of money, but in the long run it relieves a great deal of stress.

Whether you choose to have your dependant parent live in the home with you or in a nursing facility will, of course, depend largely on individual situations, jobs, circumstances, personalities, extent of healthcare required, etc. If they are in the home with you, keep in mind that

everyone must have a break occasionally. Don't hesitate to ask a sibling to take over for a few days. If this isn't possible, hire someone to stay with your parent while you take a weekend "get-away" to recharge.

Try to start as you mean to go on. It is more difficult to change directions mid-stream. Above all, don't go off on a guilt trip at the rush of mixed emotions that hit you when suddenly, you are tagged IT!

Karen Luna Ray is a freelance writer living in Oklahoma. Her father-in-law has passed on since the writing of this article and the family fabric has woven tighter as a result of their experience and loss. Ray can be reached at karenray55@yahoo.com

The Caregiver's

Home Companion

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Upcoming in May

- A caregiving spouse can spend 20-40 hours weekly taking care of mom or dad. What happens to your own home life when your spouse is absorbed in caregiving? Caregiving from the "abandoned" spouse's view.
- Getting your loved ones into an assisted living facility when the time is right. Or, moving mountains for your parents' own good, and lessons learned along the way.
- Eating your way to a good night's sleep. Practical tips and advice for caregivers and their elderly to avoid nights of tossing and turning.
- Do your parents push your buttons as you give them care? A noted psychologist outlines 7 steps to staying healthy and avoid taking their bait.