

# The Family Caregiver

Polk Family Caregivers Spring 2011 newsletter



## *“Hot” Wheels— A Chair that Rocks!*

When picking out a wheelchair for your loved one, most caregivers are interested in function. Is it a good fit? Is it easy to push? Will it fold into the truck of the car? But then most of us are picking out a wheelchair for someone who is a senior citizen. Not everyone in a wheelchair fits the elderly category.

When 17 year old Charlotte Brown, new resident to Lakeland, enrolled in Lakeland Senior High, cool wheels were just as important to her to help express her own personal style and individuality as cool wheels are to other kids her age that customize their vehicles, which are usually cars. Charlotte’s wheelchair has slanted wheels and shock absorbers for those heavy duty bumps and yes, even stairs, that she navigates on her own. Add to that flashy chrome “spinners” and metallic blue paint for the chair frame and you got a pretty jazzy ride. But Charlotte wanted other custom work for the chair where she spends all her waking hours. So her family phoned Polk Family Caregivers to ask if the Care Line knew of any place to purchase customized seat cushions. “All wheelchair cushions are just plain black. It is boring,” says Charlotte. Polk Caregivers called on our collaborating business partner, Granny Jo products, who specializes in adaptive accessories. Although Granny Jo does not make wheel chair cushions, they knew who did, the Alliance For Independence.



CHAR AND HER RIDE

Charlotte picked out 2 great fabrics from the yardage store, one in a metallic blue “goth” pattern and the other a black with beige texting abbreviation print so popular with today’s teens. Print like “LOL” and “BTW” that can only be deciphered by those chronic users of cell phones. The Alliance for Independence was able to make Char 2 unique cushions for about \$25.00 each, one to wear and one to wash, or as Charlotte says, “one for everyday and one for special occasions.” Now she rides in style, dashing from class to class. A good win for Charlotte and a good product from Alliance for Independence where the money is used to support one of our most needed nonprofit charities. Our thanks to Granny Jo products, [www.grannyjo.com](http://www.grannyjo.com), for finding this resource. For customized wheelchair cushions, contact Sharyn Lupold with the Alliance for Independence (863) 665-3846.

## ***Medicare To Offer Free Physicals to New Enrollees***



Starting this year, first-time enrollees in Medicare will be offered free physicals, courtesy of the new Affordable Care Act. The "Welcome to Medicare" benefit will be offered only during a person's first year of enrollment in Part B, and the doctor must agree to be paid directly by Medicare for the visit to be free.

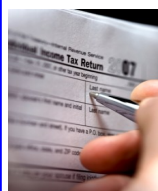
It's part of an effort to focus on preventive medicine, rather than trying to fix problems after they arise, which is much more expensive. Preventive services covered by Part B include bone density measurements, mammograms to screen for breast cancer and annual flu shots

People who have this initial consultation will then have a baseline health record, including a checklist for a plan of action, such as further cancer or diabetes screenings and vaccinations. The Affordable Care Act also makes these free to Medicare beneficiaries.

Annual checkups, which Medicare calls Wellness Exams, will still be offered after a person has been enrolled for 12 months. They too will be free if the doctor accepts payment from Medicare.

## ***Other New Provisions of the Affordable Care Act Now in Effect***

In 2011, several key provisions of the healthcare reform law will take effect, including closing the Medicare drug coverage gap. You can find new provisions... everything from nutritional labeling to long-term Medicaid coverage changes... going into effect in the new health reform law by using the Kaiser Family Foundation's interactive Implementation Timeline. Just goggle "Kaiser Family Foundation timeline."



## ***Tax Tips for Caregivers***

According to IRS Publication 502, caregivers are entitled to the following benefits:

- Dependents - You can claim your parent or other loved one as a dependent if you provide more than half of the support for a relative. This includes nursing home and assisted living expenses if you are helping with financial support.
- Wheelchair - If your loved one is in a wheelchair, the cost of the chair is tax deductible as long as the use is primarily for the relief of sickness or disability and not strictly for transportation to and from work.
- Transportation and Medical Mileage- If your loved one can't travel alone, you can also deduct transportation expenses like mileage, parking, tolls, and even meals and lodging if your main reason for being there is to get medical care.
- Homecare, nurses, in-home therapists and adult day care expenses are all deductible.
- Medical Expenses include doctor visits, surgeries, lab work, and supplies like false teeth or catheters.

To claim these deductions, you must have contributed more than half a person's support, even if you are sharing that responsibility with other family members. Secondly, your loved one must be a U.S. citizen or a resident in the United States, Canada or Mexico. Lastly, your loved one cannot have filed a joint income-tax return for the same tax year unless it was filed only to claim a refund.

## *Out and About: Upcoming Presentations by Polk Caregivers*



Strictly for professionals, the topic at the February Better Living for Seniors meeting was the new National Ethical Guidelines from the American Medical Association regarding how physicians and other medical professionals should interact with family caregivers.

After many years of negotiating with the AMA, caregivers have an outline for helping caregivers. The blueprint has 13 recommendations in all, and is an extension of previous HIPPA guidelines. Recommendations include including the primary caregiver when discussing care and treatment options. It also includes giving referral information to family caregivers, providing educational resources and checking the levels of distress that long-term illness is causing within the family. Better Living for Seniors is a countywide coalition of marketing representatives from many companies who help seniors in Polk County.



### *Savannah Court—Bartow*

March 15th, Polk Caregivers lead a discussion about the emotions that plague family caregivers forced to make tough decisions, such as rest home placement. Although it is often in the best interest of your loved one to go into assisted living or another other institution, it is often a difficult emotional decisions for families that are left feeling like somehow they have failed.



### *Lakeland Multiple Sclerosis Society*

Polk Caregivers are scheduled to be the guest speaker at the Lakeland MS Support Group, Saturday, May 14 , 10 am., United Methodist Church, 2700 S. Florida Ave. Lakeland. Topic is “Basic Caregiver Skills,” such as giving medications, helping to transfer to wheelchairs, how to make a bed with someone in it.



### *Central Florida Amputee Support Team*

Polk Caregivers is also speaking April 14th, Thursday at 6 pm, 2606 Lakeland Hills Blvd. Join us for help for those caregiving amputees. Phone (863) 984-3820 for info.

## *Welcome to New Collaborating Partners*



### **RENEWING COLLABORATING PARTNERS**

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### **NEW COLLABORATING PARTNERS**

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## *Deadly Emotions of Family Caregiving*

Most family caregivers are familiar with the backlash of emotions that result from “trying to do it all.” Before you blame yourself for not being the perfect caregiver, take a read through these common emotions that caregiver’s experience.

**1. Guilt** stems from doing or saying what you believe is the wrong thing; not doing what you perceive to be enough or otherwise not always being perfect. Caregivers often burden themselves with a long list of "oughts," "shoulds," and "musts." A few examples: I must avoid putting Mom in a nursing home. I ought to visit every day. I shouldn't lose my temper with someone who has dementia. Caregiver guilt is an especially corrosive emotion because you're beating yourself up over faults that are imagined, unavoidable -- or simply human.

**What you can do:** Lower your standards from ideal to real; aim for a B+ in various aspects of your life rather than an A+ at everything. Ask yourself what's triggering the guilt: A rigid "ought"? An unrealistic belief about your abilities? Above all, recognize that guilt is unavoidable. Because your intentions are good but your time, resources, and skills are limited, you're just plain going to feel guilty sometimes -- so try to get comfortable with that gap between perfection and reality instead of beating yourself up.

**2. Resentment** is still so taboo that many caregivers won't even admit to it. Caregivers often feel put-upon and upset because of slights by others, especially siblings and other adult children who don't do enough to help. It is pretty normal to feel your life has been hijacked by the responsibility of caring for another. Without enough support or no caregiving outlets, feelings of being ignored, abandoned, or criticized can fester into anger and depression.

**What you can do:** Simply naming this tricky emotion to a friend can bring some release. Try venting in a journal or anonymous blog. Know that resentment is a very natural and common response to long-term caregiving, especially if your work life, marriage, health, or outside activities are compromised as a result. Know, too, that you can feel this complicated emotion and still be a good person and a good caregiver.

**3. Anger** shows on some people more than others, but almost no one is *never* angry. We get mad for reasons both direct (a balky loved one, an unfair criticism, one too many mishaps in a day) and indirect (lack of sleep, frustration over lack of control, pent-up disappointment). Chronic anger and hostility have been linked to high blood pressure, heart attack and heart disease, digestive-tract disorders, and headaches. Anger can jeopardize relationships and even harm others. Managing caregiver anger not only helps your well-being but makes you less likely to take out your fury on your loved one.

**What you can do:** Rather than trying to avoid anger, learn to express it in healthy ways. Simple deep-breathing exercises can channel mounting anger into a calmer state. Talk yourself down with soothing chants: “It's okay. Let it go.” Ask yourself if there's a constructive solution to situations that make you angry. Is a compromise possible? Would being more assertive (which is different from angry) help you feel a sense of control? Laughing at absurd and idiotic behavior can provide a healthier release than snapping.

**4. Worry** is caused by good intentions, love, and wanting the best for your loved one. Worry ultimately triggers more worry and upset because it doesn't accomplish anything. Being concerned is harmless. Over wor-

ry and obsessing, however, can disrupt sleep, cause headaches and stomach aches, and lead to mindless eating or undereating.

**What you can do:** If you notice worrying thoughts interfering with getting through the day or sleeping at night, force a break to the cycle. Try setting a timer and resolve to focus on something else when the five minutes is up. Then flip negative thoughts to their productive side: How can you help? Who can you call? Are there possible solutions? And don't be shy about seeking out a trained counselor to help you express and redirect obsessive worrying more constructively.

**5. Loneliness** Your world can shrink almost before you realize what's happened. Friends may back away out of uncertainty or a belief they aren't wanted. Intense time demands lead you to drop out of outside activities. If you're dealing with dementia or other condition that alters personality or behavior, the loss of your loved one's former companionship is another keenly felt loss adding to isolation. People with large, rich social networks have different brain structures, new research finds. Loneliness seems to curb willpower and the ability to persevere, and it can lead to overeating, smoking, and overuse of alcohol. Lonely people also have more cortisol, the stress hormone, a big health risk factor.

**What you can do:** Expand your social circles, real and virtual. Arrange respite help, so you can add at least one outside activity, such as one you've dropped. Take the initiative to reach out to old friends and invite them over if you can't get out easily. Consider joining a support group related to caregiving or your loved one's illness. In online forums, you can find kinship with those who know just what you're going through. Taking care of a loved one is stressful to most family caregivers. There's never enough time for yourself – or so it seems, but meeting your own needs is vital for both you and the person you're caring for. Care for yourself, so you can care for them.

**6. Grief comes along** with coping with chronic illness, especially when witnessing losses in your loved ones abilities and the grief associated with what might have been that is forever lost.

**What you can do:** Know that your feelings are normal. Allow yourself to feel sadness and express it to your loved one as well as to supportive others; pasting on a happy face, hiding the truth and can be frustrating to the person who knows he or she is ill or dying. Make time for yourself so that you're living a life outside of caregiving that will support you both now and later.

**7. Defensiveness** Protecting yourself is good -- to a point. When you're doing so much, it's only natural to bristle at suggestions that there might be different or better approaches. Especially if you're feeling stressed, insecure, or unsure, hearing comments or criticisms by others, or reading information that's contrary to your views, which can inspire a knee-jerk response of self-protection: "I'm right; that's wrong!" While nobody knows your loved one and your situation as well as you do, being overly defensive can make you closed-minded. You risk losing out on real help. You may be so close to the situation that you can't see the forest for the trees, for example; a social worker or friend may have a perspective that points to what really might be a better way.


**What you can do:** Try not to take everything you hear personally. Instead of getting cross or discarding others' input, vow to pause long enough to consider it. Remember the big picture. Is there merit in a new idea, or not? What you're hearing as a criticism of you might be a well-intentioned attempt to help your loved one. You may decide things are fine as is, and that's great, but if you start from a point of calm and confidence, the focus remains your loved one, -- as it should, -- not on you.



## What About You?

The first quarter of a new year is a good time to remind yourself about the basics of self care. The National Family Caregivers Association published the following tips for family caregivers:

- Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage.
- Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- Watch out for signs of depression and don't delay in getting professional help when you need it.
- When people offer to help, accept the offer and suggest specific things that they can do.
- Educate yourself about your loved one's condition. Information is empowering.
- There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence. Don't do for them what they can still do for themselves.
- Trust your instincts. Most of the time they'll lead you in the right direction.
- Grieve for your losses and then allow yourself to dream new dreams.
- Stand up for your rights as a caregiver and a citizen.



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- You are living with mom while your husband is living 3 states away
- Your folks kitchen is neat as a pin but you have yesterday's dishes in the sink at home.
- Vacation for your boss is 6 days in Hawaii and vacation for you is 6 days in a nursing home.



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Polk Family Caregivers is a Florida registered 501(c)3 nonprofit charity that accepts tax deductible donations to assist in our mission of providing education, information, guidance and support to family caregivers through events, programs and services such as caregiver support groups, caregiving classes, Care Line referral information, conferences and the educational website.

#### **COLLABORTING PARTNER**

For \$65.00 annually, businesses, corporations, agencies, health and medical care providers and other professionals who wish to serve family caregivers and demonstrate their commitment and support, can become Collaborating Partners.

Collaborating Partners are entitled to discounts on newsletter advertising, inclusion in the referral information database used to assist family caregivers, the Care Line referral database, the quarterly newsletter, and vendor and event discounts sponsored by Polk Family Caregivers.

#### **DONORS**

Personal donations are also graciously accepted to benefit family caregivers.