

TAKE CARE!

Self-Care
for the Family
Caregiver™

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Working From Home: A Few Ideas for Family Caregivers

Are you struggling to make money while caring for your loved one? Are you in need of more flexible work hours to accommodate your erratic schedule? For some time, NFCA has been hearing from family caregivers who are finding it difficult to stay employed while honoring their caregiving responsibilities. Some have been forced to leave the workforce outright. Others have cut back on their work hours. Many are struggling to make ends meet. All of these family caregivers are eager to work and are desperate for ideas about how they can make money working from home.

We are pleased to tell you that we now have some specific suggestions for family caregivers in this situation. We recently read an article in *Woman's Day* magazine on this very subject. The advice and resources offered in this article provide an excellent starting point for anyone who has ever wondered if it really is possible to work from home successfully. With the gracious permission of *Woman's Day*, we are pleased to present excerpts from this article for the benefit of our readers.

“How to Make Money at Home” by Mary Hart, *Woman's Day*,
September 1, 2007. Copyright © 2007 Hachette Filipacchi Media U.S., Inc.,
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There are plenty of authentic and reliable ways to make money by working from home. The secret is knowing how to separate the scams from the real jobs. ...

...“Companies are learning they can save a lot of money by hiring home-based working moms to do projects such as word processing, writing, computer programming, even tutoring,” says Lesley Spencer Pyle, founder of Home-Based Working Moms (hbwm.com).

Most of the jobs listed below require an up-to-date computer, a high-speed Internet connection, a phone with a dedicated landline and a quiet place to work.

Customer Service Rep

Many companies, such as J. Crew, Express Jet, 1-800-flowers, and even the IRS, outsource customer service operations to third-party companies who then hire home-based workers or “agents” to take calls and orders. When you call 1-800-flowers, you may be speaking with Rebecca Doolley, a retired police officer and employee of Alpine Access, a major call center service. When you dialed the number, your call was automatically routed to Rebecca’s spare bedroom in Colorado.

Alpine Access currently employs more than 7,500 work-at-home customer service agents who take

(Continued on page 8)

INSIDE

	2
<i>Finding Normalcy in a Caregiving Life</i>	3
Tax Tips	6
<i>Resources, Reviews & Whatnot</i>	7
<i>Family Caregiving and Public Policy</i>	10
CCAN Update	11
<i>Your CCAN Representatives</i>	13
<i>New Study Reveals High Cost Of Caring for an Older Loved One</i>	14
<i>What Can I Do? Caregiver Questions</i>	

Finding Normalcy in a Caregiving Life

The following is an excerpt from *A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard*, by NFCA President and Co-founder Suzanne Mintz.

Peter Dickinson is one of my favorite authors. He writes mysteries, but they are always more than mysteries. They are beautifully crafted stories that shed light on the human experience, stories that make you stop and reread a sentence two or three more times before you are willing to leave it there on the page and move on.

In his book *Some Deaths Before Dying*, there is a sentence I've never been able to forget. It was said by the lead character, a woman who was dying from a degenerative muscle disease and at the time of the story was bedridden, able to move just her eyelids and speak only haltingly. She had been a vibrant woman who, in her healthier years, had to some extent been a caregiver for her husband, who had been a prisoner of war during World War II and came home bearing psychological scars. In referring to what had happened to her husband, and therefore to herself, she thought, "She too had been betrayed by happenings beyond her sphere, and now she was expected to live and behave like a normal citizen, despite that."

The sentence took my breath away. Indeed, isn't that what has happened to all of us who now answer to the title of family caregiver? Isn't that what has happened to the spouses, parents, partners, friends, children, and siblings for whom we care? We've "been betrayed by happenings" we couldn't control and presented with the daunting challenge of trying to recreate normalcy.

It isn't an easy thing to do, recreate normalcy when you've been hit by what feels like the equivalent of an atomic blast, and yet that is what is expected of us, and indeed what we always strive to do. But I have come to realize that for my family and other caregiving families, nor-

"Normal isn't boring at all, except perhaps to those who have never experienced the outside-the-norm situations of caregiving."

malcy is very different than it is for families that don't have to deal with disability, with the almost perverse attention to the basic acts of life that come with it and the myriad arrangements we must make to do ordinary things.

I recall once seeing a young man walking down the street. He was wearing the typical costume of his generation: jeans and a T-shirt. Blazoned across the front of his chest in bold black letters was the statement, "Normal Is Boring." I read it as he passed by me with the jaunty look of one who believes he is immortal, and I thought to myself, "He doesn't have a clue. He doesn't realize that normal isn't boring at all. It is the most wonderful thing in the world." Normal is what those of us who are family caregivers want more than anything else. We want to be like other families that take walking and talking and eating and toileting and swallowing and thinking for granted. We want our loved ones to be well. No, normal isn't boring at all, except perhaps to those who have never experienced the outside-the-norm situations of caregiving.

Steven [my husband] and I have a definition of normalcy that fits our

(Continued on page 12)

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TAX TIPS

For Family Caregivers

You may be entitled to deductions or credits that can help take some of the sting out of April 15.

Cecily Slater, CPA

Most people dread April 15. Family caregivers in particular have good reason to feel stressed about this day. The role of family caregiver, by its very nature, is one that often places you in a challenging financial position. There may be one bright spot to April 15, however. As a family caregiver, you may be entitled to deductions or credits that can help take some of the sting out of tax season. The following tips should serve as a guide for you to begin thinking about how to maximize your deductions. Tax rules change, so always check with a tax professional when you are getting ready to file.

Medical Expense Deductions: General Principles

For a deduction to qualify as a medical expense, you must have spent money to alleviate or prevent a physical or mental defect or illness. Common deductions include:

- Medical insurance premiums (unless pre-tax);
- Prescription medicines;
- Doctors' bills;
- Hospital fees for services and/or room and board; and

- Travel to and from medical appointments. (The mileage rate for 2007 is 20 cents per mile.)

You can deduct only medical and dental expenses that are in excess of 7.5 percent of your adjusted gross income (AGI). For example, if your AGI is \$25,000 and your medical expenses add up to \$2,000, you will be able to deduct only \$125. That's the difference between the \$2,000 you spent and \$1,875, which is 7.5 percent of \$25,000.

There's another catch: You can deduct only those amounts for which you have not been reimbursed by private insurance or Medicare. If you are in the upper tax brackets, some itemized deductions are phased out altogether. Deductible medical expenses are *not* subject to this reduction, however.

Special Expenses

You can claim the following special items as medical deductions:

- Oxygen and oxygen equipment;
- Special schools or homes for the mentally or physically disabled (when recommended by a doctor);
- Artificial limbs;
- False teeth;
- Eyeglasses;
- Wheelchairs and repairs;

- Crutches;
- Costs and care of guide dogs for aiding the disabled;
- Braille books and magazines if they are more expensive than regular books and magazines;
- Hearing aids and the batteries to operate them; and
- Travel costs, including lodging, to receive medical treatment.

You can also deduct expenses for equipment or improvements you've made to your home for medical reasons, but the IRS will reduce these deductions by the amount such improvements increase the value of your home. Typical equipment and improvements added initially for medical reasons include:

- Ramps;
- Widened doorways and hallways;
- Grab bars in bathrooms;
- Elevators, stair glides, etc.;
- Air conditioning; and
- Accessible shower stalls.

Unfortunately, health club dues and dancing or swimming lessons are not deductible, even if recommended by a doctor.

Nursing Home Care

Nursing home expenses, per se, are not deductible, but medical expenses

(Continued on page 4)

Tax Tips

Continued from page 3

incurred in a nursing home are. This includes the cost of meals and lodging while the patient is in the nursing home, so long as the main reason for being there is to get medical (not simply personal) care.

Nursing, Therapeutic, and/or Aide Services

Wages you pay for an attendant who provides nursing and/or personal care services are deductible as medical expenses. These services include such nursing activities as giving medication and changing dressings, and typical personal care services such as bathing and grooming the patient.

If you provide room and board, these may also be deductible, but typical household services such as cooking and cleaning do not qualify as medical deductions.

For Whom Can You Claim Medical Deductions?

You can take medical expense deductions for yourself, your spouse, and your dependents. A person generally qualifies as a dependent for medical expense deductions if he or she meets all of the following criteria:

- Is related to you;
- Lived with you for the entire year as a member of your household. (Parents, children over the age of 19, grandchildren, and siblings do not have to meet this requirement.);
- Was a U.S. citizen or resident, or a resident of Canada or Mexico, for at least part of the calendar year for which you are filing taxes; and
- You provided more than half of that person's total support for the calendar year. If you and someone else are providing more than half a dependent's support, but no one alone provides more than half, you can use what's called a "multiple support agreement" to claim the dependent, but only one of the parties to the agreement can claim medical expenses for the dependent person. (For example, in order to take the medical deduction for expenses of a parent, the adult child must be providing 50 percent or more of the support for the parent. If several siblings combined contribute 50 percent, but no single child pays the 50 percent, a multiple support agreement can be filed with the return and one of the siblings may claim the expenses.) If parents of a child with significant medical expenses are divorced, the child is considered a dependent of both parents for the medical expense deduction.

Where to Get Help

Tax law is confusing at best. If you want some additional information, here are a few ways to get it:

- The Internal Revenue Service offers a number of publications that can help you understand the deductions and tax credits to which you may be entitled. Some of the most helpful include:
 - Your Federal Income Tax – Publication 17
 - Medical and Dental Expenses – Publication 502
 - Older Americans' Tax Guide – Publication 554
 - Tax Highlights for Persons With Disabilities – Publication 907
 - Tax Rules for Children and Dependents – Publication 929

To order these publications, call 800/TAX-FORM or go to www.irs.gov and click on "Forms and Publications."

- The IRS will also answer taxpayer questions if they are not too complicated or controversial. You must realize, however, that while the IRS will try to guide you in finding the answers you need, it does not offer tax advice. To find the taxpayer service number for your area, check the local phone book under the IRS listings.
- There is only one place to go for individual tax advice, and that is to a tax professional. If you are confused about what deductions or credits may apply to you, or if you need help preparing your return, you may find it beneficial to consult someone who specializes in this area. There are a number of tax services available and you can find their numbers in the phone book, but the best reference may well be word of mouth. Talk to people you know and respect and ask them for a referral. ■

Cecily Slater is a certified public accountant who has been providing tax and financial planning advice to individuals and businesses in the greater Washington, D.C., area since 1979.

I Need Help!

Family caregiving is more than a one-person job. The founders of Lotsa Helping Hands know this firsthand and, out of their shared experience, they found a way to make life easier for caregiving families everywhere.

WWW.NFCA.LOTSAHELPINGHANDS.COM is a

- Calendar
- Meeting place
- Confidential repository for medical information
- Way for friends, colleagues and others to let you know they care
- Way to get the help you need without having to ask constantly
- Way to get the help others want to provide when you don't know how to communicate your needs

Check it out yourself and, better yet, send the link to a friend.

Lotsa Helping Hands is a FREE service of the National Family Caregivers Association.



The Home-Caring Brand®
TRANQUILITY
 Incontinence Products®

Continence Assessment

C.U.P. Capacity Under Pressure

Please use this form to assess incontinence need. Write the number that best describes the incontinence level. Add the assessment numbers for the total score and select the appropriate category of product based on the total score.

Continence Level - Urinary

- 0 - *Continent*; individual is not incontinent
- 1 - *Usually continent*; individual is rarely incontinent; may have one episode per week
- 2 - *Occasionally incontinent*; may have a couple of episodes a week; but not daily
- 3 - *Frequently incontinent*; incontinent daily; but may have periods of continence
- 4 - *Incontinent*; multiple episodes of incontinence throughout the whole day

Continence Amount - Urinary

- 0 - *Continent*
- 1 - *Light*; less than 3.4 oz. per episode
- 2 - *Moderate*; 3.4 - 10.1 oz. per episode
- 4 - *Heavy*; 10.1 - 16.9 oz. per episode
- 6 - *Super Heavy*; greater than 16.9 oz. per episode

Continence Level - Bowel

- 0 - *Continent*; no fecal episodes
- 2 - *Light*; occasional fecal smears
- 4 - *Moderate*; occasional fecal episodes
- 6 - *Incontinent*; fecal incontinence

Toileting Ability/Mobility

- 0 - *No assistance*; ambulatory
- 1 - *Minimal assistance*; may need a little help with sitting up
- 2 - *Moderate assistance*; needs physical assistance from at least one caregiver
- 4 - *Unable/immobile*; unable to ambulate to bathroom/cannot use commode or bedpan

Mental/Physical/Level of Orientation

- 0 - *Oriented*; the ability to communicate
- 2 - *Slightly confused*; sometimes communicates needs
- 4 - *Confused*; unable to communicate needs
- 6 - *Skin condition is fair to poor*; breakdown exists or is likely

Total Score

Use the total score to find the best solutions for the appropriate incontinence level. (See **Score Column** to Identify **Product Category**)

1
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Protection Level

Light



Moderate



Heavy



Maximum



Added



The measure of "fluid capacity" of ALL Tranquility absorbent products uses a test method that simulates wearing conditions. The test exerts **pressure** on the product after saturation.

The amount of moisture that is retained after pressure is applied is the value that is displayed on packaging and reported in catalogs as **ACTUAL** fluid capacity for each absorbent product and every size. Absorbent products absorb more fluid under "free-swell" conditions than they can retain under pressure. Loved ones that are using incontinence products are sitting, standing, walking, and lying down - all of which exert pressure on the product.

Loving caregivers are acutely aware that **RETENTION** is a key factor in incontinence management.

1^U = 8 oz = 236 ml

C.U.P. = Capacity Under Pressure
 Liquid absorbed by product that cannot be forced out

Feel confident in choosing Tranquility as your incontinence solution. There is a full line of all sizes and levels of protection from which to select. And every one is backed by the Peach Mat Guarantee that promises skin dryness, odor reduction, pH neutralization and inhibition of bacterial growth.

Call the Tranquility Care Center with your "score" for a confidential consultation and FREE samples of a product just right for you or your loved one!

1-866-865-6055

Visit www.tranquilityproducts.com for more information.

As its title implies, the purpose of this column is to provide you with useful information and help you tap into new networks or learn about available products and services.

Do you want to know more about environmental hazards? The Environmental Protection Agency (EPA) has issued a series of fact sheets on environmental hazards (air pollution, heat, water) for older adults and family caregivers. The fact sheets are part of the EPA's aging initiative, an effort to protect the health of older adults from environmental hazards. As we age, our bodies are more susceptible to environmental hazards, which contribute to a worsening of chronic or life-threatening conditions. In addition, older persons have accumulated a lifetime of environmental and occupational contaminants, which may remain in their bodies.

The fact sheets are available in several languages as well as low-literacy and low-vision versions. They include such titles as "Diabetes and Environmental Factors," "Effective Control of Household Pests," "Planning for Excessive Heat Events," and "Women and Environmental Health."

To download these free publications, go to: <http://epa.gov/aging/resources/factsheets/index.htm#fs>.

Are you caring for an older adult?

The Council for Jewish Elderly (CJE) has created an educational and informational Web site, "CAREgiving Help," to serve as an Internet-based service for spouses, family members, and others who are caring for older people. The Web site offers information relevant to a wide range of caregiving situations and is designed for those who are new to caregiving as well as those who have been providing care for some time. It also provides information and resources for families that are handling care-related decisions from out of town.

The site includes: educational videos and other materials that illustrate common issues, demonstrate specific tasks or skills, or provide suggestions for those who are caring for

older people; frequently asked questions to guide those new to caregiving to appropriate information and resources; a message board that provides caregivers with the opportunity to ask questions and receive answers from a geriatric care specialist; relaxation and reflection exercises designed to provide caregivers with brief opportunities for themselves and ways to relieve stress; and a comprehensive resource page with links to other Web sites, organized by topic. To learn more, go to www.caregivinghelp.org.

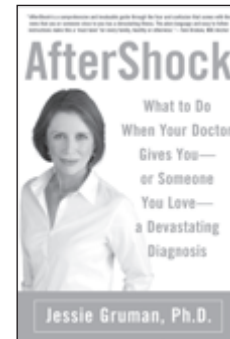
Is your loved one suffering from a movement disorder?

WE MOVE is a not-for-profit organization that provides education and information about the latest clinical advances in, management of, and treatment options for neurological movement disorders to patients, professionals, and the public. The Web site links you to a wealth of information on a variety of movement disorders, as well as useful resources, discussion groups, Webinar presentations, and more. In addition, visitors to the Web site can subscribe to a patient-friendly news service and search a directory of physicians who diagnose and treat adult and pediatric movement disorders or provide physical medicine and rehabilitation. To learn more, go to www.wemove.org.

BOOK REVIEW

AfterShock: What to Do When the Doctor Gives You – or Someone You Love – a Devastating Diagnosis by Jessie Gruman, Ph.D. (Walker & Company, 2007, \$16.95).

How did you feel when your loved one first received his/her diagnosis? If you are like most people, you probably felt shock, and you were unsure how best to help your loved one or yourself. Jessie Gruman knows all about shock, having survived three devastat-



ing diagnoses herself. Her book, *AfterShock*, was written to help others who find themselves suddenly dealing with a life-threatening or

life-altering diagnosis, and it's a valuable tool to turn to when that diagnosis first hits home.

In *AfterShock*, Gruman speaks from experience and from the heart. To make all the information easier to digest, each chapter begins with a specific objective, such as getting a second opinion, finding the right doctor, and involving family. The chapters then go on to show, with heartfelt quotes, how others have tackled these issues. Finally, Gruman offers specifics about where to find reliable information and resources. *AfterShock* is written for anyone who is feeling overwhelmed by the amount of information that needs to be absorbed immediately following a devastating diagnosis. Do you need to get acquainted with a specific disease and its treatment? Read Chapter 2. Do you need a few tips to help your loved one get timely care? Start with Chapter 6. For the family caregiver, *AfterShock* "recognizes your critical role in helping and supporting the person with the diagnosis as he makes some of the most important decisions of his life." The book is meant to be a calming force within the storm of information and emotion overload.

AfterShock: What to Do When the Doctor Gives You – or Someone You Love – a Devastating Diagnosis is available wherever books are sold and at www.walkerbooks.com.

The Book Review was provided by CCAN representative Liz de Nesnera.

Family Caregiving and Public Policy: Principles for Change

In 2003 a group of family caregiver advocates, including NFCA, got together to draft a Statement of Principles to serve as the foundation for healthcare and long-term care policy reform. At the time, more than 40 national organizations endorsed these principles. Much has happened between 2003 and today, but the principles are just as sound now as they were when first developed. They are worth noting as you evaluate our presidential candidates.

PRINCIPLE 1: Family caregiving concerns must be a central component of healthcare, long-term care, and social service policy making.

PRINCIPLE 2: Family caregivers must be protected against the financial,

physical, and emotional consequences of caregiving that can put their own health and well-being in jeopardy.

PRINCIPLE 3: Family caregivers must have access to affordable, readily available, high-quality respite care as a key component of the supportive services network.

PRINCIPLE 4: Family caregivers must be supported by family-friendly policies in the workplace in order to meet their caregiving responsibilities. Examples of family-friendly workplace policies include: flextime; work-at-home options; job-sharing; counseling; dependent care accounts; information about and referral to community services; employer-paid services of a care manager; and more.

PRINCIPLE 5: Family caregivers must have appropriate, timely, and on-going education and training in order to successfully meet their caregiving responsibilities and to be advocates for their loved ones across care settings.

PRINCIPLE 6: Family caregivers and their loved ones must have affordable, readily available, high-quality, comprehensive services that are coordinated across all care settings.

PRINCIPLE 7: Family caregivers and their loved ones must be assured of an affordable, well-qualified, and sustainable healthcare workforce across all care settings.

PRINCIPLE 8: Family caregivers must have access to regular, comprehensive assessments of their caregiving situation to determine what assistance they may require. ■

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Did you know the proceeds can be used for any reason, **including providing care for a loved one?**

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Call today for a free consultation.
301/656-8622



A New Look at Life Insurance

Are you missing the luxury of warm, relaxing baths?

If you or a loved one has given up bathing because of age, mobility or safety concerns, the Archimedes Bath Lift by Mangar International is the answer. It is so simple, you'll wonder why no one thought of it earlier. The battery-operated "chair" safely and steadily lowers you to the bottom of the tub, and when you're done bathing, it gently raises you back to the top of the tub assuring a comfortable and safe exit from the tub.

Rediscover the pleasure of a warm, relaxing bath with our exclusive home trial. Try the Archimedes Bath Lift for up to 90 days, and if you are not completely satisfied, simply return it for a refund of the product purchase price.* Call today.



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Item # ZR-4880

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Working From Home

Continued from page 1

in-bound calls (there's no outbound or cold calling) for dozens of companies. "This works perfectly for me because I can set up my hours around my family's busy lifestyle," says Rebecca, who usually works 20 to 32 hours a week, depending on her schedule.

While the typical hourly rate is about \$9, Alpine Access agents can earn up to \$20 an hour with incentives and bonuses. Rebecca also receives benefits and a matching 401(k) plan. (Some companies consider their staff independent contractors, so they don't provide benefits.) Go to alpineaccess.com. Other companies that hire virtual call agents:

- LiveOps.com
- Arise.com
- WestatHome.com
- WorkingSolutions.com
- ACDDirect.com

Virtual Assistant

Many small-business owners and mid- to executive-level professionals need personal assistants, but can't afford a permanent position on the payroll. The solution? Hire people from remote locations to do their administrative work.

Virtual assistants handle all kinds of administrative projects, including travel arrangements, event planning, correspondence and other support services that can be done remotely via e-mail and phone.

Lynne Norris, who works out of her home in Pennsylvania (Norris-BusinessSolutions.com), says that rates for VAs run about \$25 to \$75 or more an hour, based on the types of services you provide. The startup costs are about \$500 to \$1,000, assuming you have an up-to-date computer and printer. Lynne loves the flexibility. "My children are happy that I don't miss the important things in their lives." Check out the International Virtual Assistants Association (ivaa.org), or virtualassistantjobs.com and teamdouclick.com for more.

Online Tutor

If you have a college degree and the skills to tutor students online in math, science, English or social studies, this job may fit you perfectly. Go to Tutor.com — tutors who work for the company and have passed their probationary period earn \$10 to \$14 an hour.

Nurse on Call

If you are a registered nurse, you may be able to supplement your income by working for a company that provides phone-based triage and medical information to its customers. You may be dealing with a pharmaceutical company, insurance company or other health-related organization. Take a look at Fonemed.com, a company that hires phone-triage nurses to provide this type of health-related service from their homes.

Telemarketer

To do this job, you need a pleasant voice and personality, and really thick skin — you're bound to encounter some hostility. Still, it's a good way to earn income. Many large companies now outsource their cold-calling campaigns to third parties who hire home-based workers to place the calls. Telemarketers are typically paid by the hour, and they may earn incentives and commission based on performance.

Companies hiring home-based workers include West.com, Telereach.com and Intrep.com. Apply on their Web sites. Keep in mind that a legitimate company will typically not require you to pay a fee to get information or leads, and will explain how to apply, exactly what is required and what to expect.

Online Juror

Companies will pay you to sit on mock juries to give attorneys and other jury consultants feedback on cases they are currently handling. Think of these as focus groups. The cases are real, but your verdict will

Avoid Work-at-Home Scams

It's not always easy to figure out if a company is legitimate. Try these tips from the attorney general of the state of New York:

- Check with the Better Business Bureau in your area and the area in which the company is located.
- Ask questions, including: what specific tasks you'll have to perform; whether you will be paid by salary or commission; and who will pay you. Also, ask about the total cost to you, including supplies and equipment.
- Be wary of overstated claims of product effectiveness, exaggerated claims of potential earnings, and demands that you pay for something before instructions or products are provided.
- Be wary of personal testimonials that never actually identify the person so you can't investigate further.
- Contact your state attorney general's consumer help line if you believe you've been victimized by a work-at-home scheme.

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do little more than give those involved a prediction of how things might go. You can earn fees ranging from \$5 to \$50. Be sure to read all the disclaimers and details. Go to:

- ejury.com
- onlineverdict.com

Survey Taking

I'd pretty much ruled out survey taking as a legitimate way to earn money from home, but then I heard from Bonnie Alcala. She and her daughter Andrea Spain, an elementary school substitute teacher, take surveys online for fun and a little profit. They are careful to avoid any scams by refusing to pay an upfront fee or other charge. Bonnie and Andrea pocket around \$100 a month for spending two hours a week taking surveys, which gives each of them extra pin money. In addition, they collect all kinds of gift cards and other prizes.

If you've got a little spare time and want to save up a stash of cash for holiday shopping or even a family vacation, here are Bonnie and Andrea's favorite survey sites:

- your2cents.com
- npdor.com
- surveysavvy.com
- acop.com
- viewpointforum.com
- epoll.com
- greenfieldonline.com
- mysurvey.com

Cyber Crafter

If you're a crafter in search of customers, the Internet is your showcase, and not only at auction sites like eBay.

Even though Jamie Beck of *WaxingMoonCreations.com* and DeWitt Young of *ObviousFront.etsy.com* have never met, they have something in common: They turn their crafts into cash in cyberspace. Both have booths at *Etsy.com*'s Craft Mall, an amazing place where more than 10,000 artisans and crafters offer their goods for sale.

Jamie creates beautiful clean-burning, soy-based candles from her home in California. DeWitt turns salvaged parts from old TVs and VCRs into artsy necklaces, earrings and figures.

"Etsy is a fabulous venue for crafters," says Jamie. "The site is designed for customers to purchase original arts and crafts from artisans. I've found that joining groups with other Etsy crafters for support has been very valuable."

These ideas from Woman's Day should help you start thinking about what type of job might work for you. There are many other jobs that lend themselves to working from home, including medical transcription, proofreading, and bookkeeping, to name just a few. What's clear from the article excerpts above is that it's important to think "outside the box." Start by defining what skills and experience you have to offer and then check out Web resources, scan the employment section

of your local newspaper, and talk to people you know. It may take a little time and persistence, but the answer to more flexibility and financial independence may be closer than you think. ■

** Editor's Note: When typing in a Web address listed above, it should always begin with "www." While every effort was made to verify the accuracy of the resources listed, readers should use their own discretion when evaluating and/or acting upon any information provided.*

Do You Work From Home?

If your answer is "yes," we want to hear from you. You can help other family caregivers by sharing your experience with us. E-mail editor@thefamilycaregiver.org or send a letter to the address on the masthead and help inspire others.

NFCA's action-oriented messages are inspiring and empowering.

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CCANers Initiate Family Caregiver E-Communities

Debby Halpern

The Caregiver Community Action Network (CCAN), made up of NFCA's state volunteers, has kicked off a wonderful new program called Caregiving E-Communities. To date, there are e-communities running in New Jersey, Michigan, Virginia, and Nebraska.

The e-communities serve as a resource center and connection point for family caregivers from across each state to help one another through the maze of information, referrals and support. The program is designed to foster a healthy exchange of ideas among caregivers and to provide insights and feedback on experiences that could lessen the burdens inherent in family caregiving. Members are finding that this community helps provide support, education, empowerment and advocacy. CCANers moderate the e-communities, which meet the following needs:

- Personal – Each family caregiver who uses the service is able to voice his/her own needs and concerns and solicit the help of others.
- Easy to use – It's as simple as sending an e-mail.
- Interactive – Family caregivers are offered the opportunity to share with one another and exchange feedback and ideas.
- User-scheduled – There is no predetermined time at which family caregivers need to "report" to participate in these communities.

Each moderated e-community allows members to post questions or comments, respond to other members' posts, or simply read through postings to glean information that the reader finds helpful. Each also

contains a directory of services and resources, with feedback from the individual posting the listing — an invaluable resource to caregiving families as they make critical decisions. CCAN volunteers ensure quality control in the operations of the e-community and help to connect individuals seeking assistance to services, resources and information. This effort is made possible thanks to a grant from the Retirement Research Foundation.

To join one of the e-communities for the pilot states listed below, simply send an e-mail to the moderator at the address indicated. All family caregivers from these states are invited to join.

CCAN e-communities are now operating in:

Michigan: MIFamilyCaregivers-subscribe@yahoogroups.com

Nebraska: NEFamilyCaregivers-subscribe@yahoogroups.com

New Jersey: NJfamilycaregivers-subscribe@yahoogroups.com

Virginia: VAfamilycaregivers-subscribe@yahoogroups.com

If you live in another state and would like to help launch an e-community to service family caregivers where you are, please send an e-mail to ecom@thefamilycaregiver.org and let us know that. We are opening more e-communities throughout the year and will let you know as states are added.

We are always looking for more dedicated volunteers. For more information on the CCAN program, contact Linda Jones at 248/358-1186 or linda_jones100@hotmail.com. ■

Debby Halpern is NFCA's communications director.

"The family caregivers I am in touch with now seem more open to learning about the resources that are available and want to get connected to them. Helping them do that is very fulfilling."

– CCAN volunteer
Carol Hilf, Bloomfield, MI.

CCANers Wanted

Are you looking for a way to help others? NFCA is in search of new CCANers in the following areas:

Indiana
Nevada
Oregon
Utah
Washington, D.C.

If you are interested in helping other family caregivers, e-mail linda_jones100@hotmail.com.

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Finding Normalcy in a Caregiving Life

Continued from page 2

current circumstances, a definition that inevitably changes over time, as his multiple sclerosis continues to take its toll and impact our collective lives. These days our definition of normal includes the fact that Steven still has some strength in his legs and arms and therefore can be an active participant in helping me help him with transfers, showering, dressing, toileting, and eating. When the time comes when he can no longer do that, we will need to find other ways to deal with these basic life activities. Most likely we will need to get a lift of some sort. Regardless of what decisions we make down the road, the new situation we will be living with will, by definition, become our norm, at least after the transition period from the old way of doing things to the new way is completed. What normal means for Steven and me is most likely quite different from your definition, especially if your caregiving situation is not the same as ours. How we each define normalcy isn't important, but what is important is finding a way to live comfortably with the

Dark Thoughts

Spouses, siblings, parents,
children

Tied to an illness not our own,
Caught in its grip, covered by
its gloom.

Living in two worlds both
healthy and ill.

We are shadows of people
crying in the dark,
Beset by fear, anger, and pain.
Wanting at times to be alone.
Needing at times to be apart.

— anonymous family caregiver

norms that are now part of our lives, and to recognize that in the world of a caregiver what's normal today may no longer be what you consider normal a year from now.

I haven't decided whether it is easier to redefine normalcy when the changes come gradually or when they come because of a more dramatic occurrence. Certainly gradual change is easier to assimilate into our lives, but it lacks the clarity of catastrophe, and doesn't always give us the opportunity to recognize the change for what it is because it sort of oozes its way slowly into our lives. But regardless of whether the changes come swiftly or slowly, they play havoc with our emotions, and we are forced to deal with what I have come to think of as the bridge between anger and acceptance.

Anger and Acceptance

Anger is an emotion we have been taught to try to hide, but these days I think of it as a very healthy emotion, one that reminds us that we are very much alive and that we burn with the fire of desire for the good things of life. Expressing our anger at the difficulties we face, the indignities we must endure, at the complex arrangements we have to make to do what should be simple tasks done by rote, is healthy. To rail at the gods is OK — for a time. But anger that is continuous, that can't be soothed, that lies buried beneath a calm exterior and festers like a dirty wound isn't healthy. Anger must eventually give way, move beyond itself to acceptance of our situation — not placid acceptance that saps our energy, but a dynamic acceptance that translates into actions that help us make the most of our transformed lives.

How do we do that? I don't know that there is one set way. We must each find our own answers to that question. I can tell you about my own experience and hopefully there will be something in it that you can grab onto to help you move beyond

any anger you may be harboring. For me it is about conscious decision-making, about making choices. Crossing the bridge from anger to acceptance is about consciously saying, and believing, that this is where I want to be. It is about choosing to take on the responsibility of caregiving. To me, that is very different from believing that I am forced to do so. I believe that despite the difficulties we confront, life awaits us. For sure it challenges us, more than it does the families of the able bodied and mentally fit. We all wish it would challenge us less, but it is the hand that we have been dealt, and the artistry of our lives is defined by the picture we create with our "other than normal" assortment of crayons. I am not saying it is easy. It is, to be sure, a crooked path, a wobbly bridge, and I have no idea what lies around the next bend; but I am no longer feeling that I was forced to be on this path, and that's the difference. Like the Robert Frost poem in which two paths converge in a wood, I am choosing to walk on the one less traveled. I am choosing to be a family caregiver.

My life has been "betrayed by happenings beyond my sphere" and for many years I could not accept that. But I slowly crossed the bridge and consciously chose to accept my new reality, and now with open eyes I act very purposefully and strive to "live and behave like a normal citizen." And I invite you to do the same: to recognize the emotions that caregiving has evoked in you; to embrace the inner strength that comes from dealing successfully with difficult situations; and to try to move beyond the frustration, the sadness, the isolation, and the other difficult emotions that so often come with being a family caregiver. Try to look inside yourself to see if you are harboring anger, as I was. If you can recognize it, you might just be able to use that energy in a more positive way to be proactive and take charge of your life. ■

New Study Reveals the High Financial Cost of Caring for an Older Loved One

If you are feeling financially pinched because you are caring for an older relative, you aren't alone. A new study reveals that half of those caring for a loved one 50 years or older are spending on average more than 10% of their annual income on caregiving expenses. Additionally, these family caregivers are sacrificing their own long-term financial and personal well-being in the process.

The study was conducted by the National Alliance for Caregiving, a coalition of organizations with an interest in caregiving, and was funded by Evercare, the nation's largest provider of healthcare coordination programs.

The *Evercare®/NAC Study of Caregivers – What They Spend, What They Sacrifice* revealed that family caregivers, who have annual median income of \$43,026, spend an average of \$5,531 a year on caregiving. This amount is \$400 more than the average American household spends each year on healthcare and entertainment *combined*, according to the Bureau of Labor Statistics. For those family caregivers who earn less than the median income, the financial burden is even greater.

Key Findings From the Study

- One in three respondents (34%) had used some of their savings to cover the cost of caregiving and one-quarter (23%) said they had cut back on their own healthcare spending.
- The most common caregiving expenses respondents cited were: Household goods, food and meals (42%); travel and transportation costs (40%); medical co-pays and pharmaceuticals (31%); medical equipment and supplies (22%); and clothing (21%).
- Long-distance caregivers had the highest average annual expenses (\$8,728), followed by co-resident caregivers (\$5,885) and those who cared for someone living less than an hour away (\$4,570).
- More than half of the respondents (53%) did not work while 37% said they had quit their job or reduced their work hours.
- Respondents spent on average 35.4 hours a week caring for their loved ones, with 19% providing care for more than three years and 32% caregiving for more than five years.
- To accommodate the caregiving time and expenses they incurred, respondents were making the following sacrifices: cutting back on leisure activities (49%) and vacations (47%); saving less or not at all for their children's future (38%); using their savings (34%); cutting back on basics such as clothing, utilities or transportation (27%) and groceries (25%); and cutting back on personal medical or dental expenses (23%).
- Respondents experienced a ripple effect of physical and emotional consequences associated with their caregiving role. These included: heightened stress or anxiety (65%), difficulty sleeping (49%), increased financial worries (43%), depression or hopelessness (37%), and new or worsening health problems (26%).
- The most significant sacrifice cited by respondents was their

own time spent caring for an older loved one, although most of the caregivers surveyed still saw their caregiving role as a labor of love and one they do willingly.

The study findings were the result of a telephone survey of 1,000 family caregivers. In an attempt to gain a more detailed understanding of the

.....
“... family caregivers, who

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a year on caregiving.”

sacrifices that these individuals make, 41 of the telephone respondents were asked to keep a detailed diary of their expenses for 30 days. The diarists spent an average of \$1,029 on caregiving over the one-month period.

This amounts to \$12,348 over the course of a year, a figure that is twice the average of the other respondents. The study did not determine why this discrepancy existed; however, one possibility is that the diarists who were recording all their expenditures kept more accurate records of their costs than those who participated in the telephone survey alone.

While the study focused on the financial toll experienced by the millions of Americans who are caring for an older loved one, it clearly illustrates the considerable price that all family caregivers pay — financially, physically, and emotionally — to fulfill a role that is essential not just to the well-being of their loved ones but to society as a whole.

The study is significant in that it quantifies what family caregivers have been saying for years: The costs associated with caregiving are enormous. It's time for legislators to take note and to take action to help America's family caregivers. ■



What Can I Do? is a question and answer column aimed at helping to meet the needs of individual readers. Answers to questions in this issue were provided by Barry Jacobs, PsyD, Director of Behavioral Sciences for the Crozer-Keystone Family Practice Residency Program of Springfield, PA. Dr. Jacobs is a clinical psychologist who specializes in family caregiving issues. His first book, *The Emotional Survival Guide for Caregivers — Looking After Yourself and Your Family While Helping an Aging Parent*, was published in June 2006 by Guilford Publications. Go to www.emotionalsurvivalguide.com to learn more.

If you have a question you would like us to answer, please send it to:

What Can I Do?
 c/o TAKE CARE!
 10400 Connecticut Ave., Suite 500
 Kensington, MD 20895-3944
 e-mail: info@thefamilycaregiver.org
 Subject Line: What Can I Do?

Q I was the primary caregiver for my husband, who just died after a long battle with cancer. I believe I was a good wife even though my husband was not a warm man. When he was diagnosed with cancer, he became even nastier. I stayed and took care of him as best I could. After my husband died, I discovered that he had an affair after he was diagnosed with cancer. I also discovered that his family has been saying very hurtful things about me. His family was never very supportive of me, and their behavior is now becoming toxic. We live in a small town so I cannot just avoid them or their friends. I don't want to move because I grew up here and I love it here. I am so upset and feel so much anger, at both my husband and his family. What can I do?

A It is hard enough mourning the loss of a spouse, but your hurt has been deepened by heinous betrayal and insult. While your grievances are more than legitimate, becoming mired in upset and anger is not in your interest. Doing so will prevent you from developing a new and happier life — one with greater and much deserved appreciation for your efforts. The challenge ahead is dealing with the pain from the past and still going forward. Here are some ideas to try:

- There is some small consolation in knowing that, by tending to your husband, you upheld values that are important to your sense of yourself. Making sacrifices, aiding a loved one, fulfilling marital vows — these are choices that you made because you believe that they are the right things to do. These values and choices should be lauded, not mocked. If your

husband and his family members couldn't appreciate them, then they are the poorer for it.

- Understanding why others behave as they do under adverse circumstances can give you some basis for removing the sting from those actions. Family members typically use anger as a means of avoiding sad feelings. In badmouthing you, your husband's relatives may be pushing away overwhelming grief. By the same token, it is not unheard of for people with terminal illness to turn on those closest to them as a kind of protest against their predicaments. Your husband may have hated his dependency on you and consequently made a romantic conquest to try to maintain his sense of potency. These are not excuses for their actions; they are inexcusable. But they are rationales for how human beings can act wretchedly under severe duress.

- I'd recommend taking the high road nowadays with your husband's family members. They can say whatever they want; don't bother responding. Your neighbors and peers in your small town will recognize your integrity and their boorishness.

None of this will be easy. Your upset and anger may be stoked by further hurtful words and incidents. If the feelings become unbearable, then pastoral counseling or psychotherapy may be of help. But hold your ground geographically and morally: If you still love your town and want to establish a new life there, then don't let them drive you away. If you consider yourself a good person regardless of the unjust ways you've been treated, then take pride in the caregiving you did.

Q My sisters and I are dealing with a rapidly deteriorating situation involving my father's wife (not our mother). Our dad is 89, largely homebound as a result of a stroke several years ago, and his wife is becoming increasingly unstable mentally and is acting out against family members (especially against one of my sisters and me) in wild and disturbing ways. My dad and his wife have become quite isolated, mostly due to her paranoia about any outside help. Following my father's stroke several years ago we were helping out with private pay aides, but my father's wife eventually rejected this help because she decided we were plotting against her. It's become a rather urgent situation. If we can't find someone to gain the wife's trust, I fear that eventually we may have to take some legal action against her given her actions of late, but this is our least favorite option. We'd love to find someone to mediate, but have absolutely no clue who intercedes in these types of situations. What can we do?

A Under the best of family circumstances, relationships between adult children and stepparents can be fraught with reticence and mistrust. Oftentimes, there's competition over the parent/spouse's love and loyalties. In caregiving situations, there frequently are struggles over the power to make medical and care decisions. But you have described the worst of circumstances: If your stepmother wasn't inclined to put stock in your concerns before, her paranoia (whether from dementia or delirium) will cause her to feel threatened by literally anything you say or do. You rightly realize that you won't be able to win her confidence. It's questionable if anyone will.

Let's focus on your dad first, however. Even though he's been physically disabled by his stroke, he may still retain adequate thinking skills. If that is the case, would he be will-

ing to make care decisions for himself, even if his wife opposes them? Could he exert his influence over her to persuade her to accept such changes? Could he even coax her to undergo a medical evaluation? I suspect you've already considered these options and, for one reason or another, it isn't possible to resolve this crisis through your father.

Another possible tack is to enlist the help of your stepmother's family members, especially her adult children, if she has any. Could they convince her to go to a neurologist, geriatric psychiatrist, or even a family doctor to be assessed for Alzheimer's dementia (the most likely source of her paranoia) or some other neurological or metabolic condition? A physician could prescribe a short course of an antipsychotic medication, which would greatly improve your stepmother's judgment. But if she resists undergoing such an evaluation, attempting

to insist that she have one will only incite her mistrustfulness further.

The legal recourse of seeking guardianship of your father — though expensive and unpleasant — has much to recommend it. By petitioning the courts for control over your father's care (if he is, in fact, incapable of making decisions for himself), you will be able to take steps to assure his safety. A legal confrontation with your stepmother will also likely foment a crisis in which her deteriorating judgment will become more evident to others who care about her. They may then initiate their own legal proceedings to have her declared incompetent and then literally force her to get the medical help she desperately needs. Ultimately, this is in her best interest. In a roundabout way, it may also preserve her marriage to your father by helping create conditions in which they can care for one another with a greater degree of reasonableness. ■



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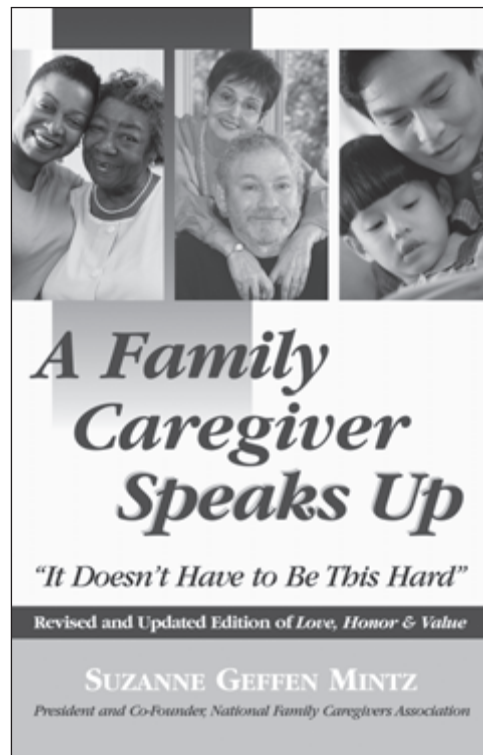
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— Judy Woodruff, Senior Correspondent
for the NewsHour with Jim Lehrer

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Speak Up With NFCA

In celebration of NFCA's 15th anniversary, we encourage family caregivers to Speak Up for their rights.

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- Your own needs as a family caregiver
- The needs of your loved one
- The rights of all family caregivers

To learn more about ways to Speak Up, become part of NFCA's family caregiver community by visiting www.thefamilycaregiver.org.

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