

Strategies & Resources for Involved Families & Caregivers

# FAMILIES

OF LOVED ONES

Summer 2009

Volume 5, Issue 2

**NEW  
FEATURE!**

*“HIGHLIGHTS  
FROM HOME”*

**ACCOMMODATIONS  
WITH STYLE**

**COMPASSION  
FATIGUE**

***CAN WE BURN OUT?***

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**NEW FEATURE  
HIGHLIGHTS FROM HOME**

**4**

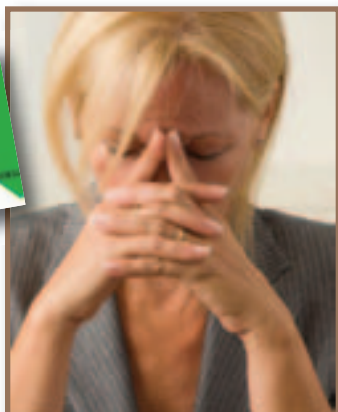


A New Jersey Couple recreates a beautiful home environment with accommodations

**COMPASSION FATIGUE**



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Are YOU  
Caring for the Caregiver?*

**"Just Sign Here..."**

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Learn how Your Signature can affect how Professionals Communicate with Your Family

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**FAMILIES OF LOVED ONES**  
 Strategies and  
 Resources  
 for Involved  
 Families & Caregivers



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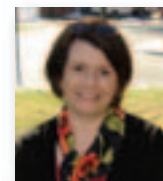
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Photo: R Cantwell

**Compassion**



From the Editor:

What makes compassion different from empathy?  
 Compassion *includes* the desire to offer assistance  
 once you have recognized someone's suffering.

In this issue of Families of Loved Ones, we are focusing on compas-  
 sion's full spectrum. On one end we look into a family's life where  
 compassion is in action, all the way through to exploring the phenome-  
 non of compassion fatigue among professional and family caregivers.

As we delve into this wide range of possibilities we can begin to see  
 the potential that the human spirit holds. In our new feature **Highlights  
 From Home**, you'll meet Carol and Tony. Their experiences help to  
 give us a clear understanding of how we can learn from those who have  
 gone before us and are teaching by example.

Do you consider yourself compassionate, sympathetic, or empathetic  
 or are you simply worn down? Do you see possibilities where others  
 may not, or does helplessness disarm your desire or ability to take  
 action? What is your style today, how are you preparing for tomorrow?

Ideally, compassion should not diminish one's own identity but  
 enhance it and those who are touched by your actions. Building key  
 life skills or developmental assets, such as resilience and honesty, can  
 help prepare a child for the future. As adults, traits such as fostering  
 independence (*within context*), helping individuals forge partnerships  
 and committing to compassion with a purpose, can serve to inspire.

To that end perhaps it is time to revisit **FOLO's Top 10 List for  
 Caregivers**. (See page 5) This list was developed early in FOLO's  
 publishing days and serves as a reminder to those who are entrenched  
 in the care of others.

Be compassionate with yourself first—because when you thrive, you  
 can be a little stronger for those who depend on you. It's a win-win!

As always, let us know your thoughts.

*René Cantwell*



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*Strategies and Resources for  
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..... *Highlights From Home*

# Making Home Work

**M**Meet Carol and Tony Sokol, a tenacious couple working hard to maintain their lifestyle.

Blessed with a close-knit family and plenty of grandchildren, Carol and Tony are the grandparents they always hoped they'd be, despite the fact that Carol suffered a stroke to her spinal column two years ago. "Carol is always cooking," Tony boasts. "We love having the kids here."

Carol and Tony are still able to entertain at their home thanks to key renovations that Tony, who worked in construction for many years, made to their small Cape Cod house. Tony built an addition with an expanded kitchen and new Great Room and transformed the old kitchen into a bedroom and new bathroom - all to ensure that Carol's environment at home would allow her to be as self-sufficient as possible.

Together they explained how despite the temptation to rush, they took particular care in making sure the modifications worked for Carol. For instance, when laying out the kitchen they used mock cardboard cabinets before installing the actual hardware. "I wanted to make sure that every inch was customized to exactly what Carol needed," Tony says. "Now when she is busy working in the kitchen we both appreciate that when she stretches her arm to reach for something, it will be exactly where it needs to be."

Carol and Tony know that they are blessed to have each other, their family and their lives together. Their advice to those who may be faced with similar circumstances:

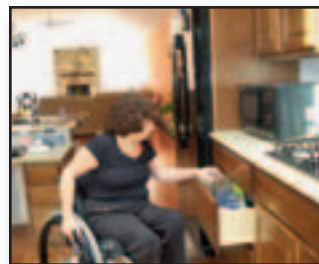
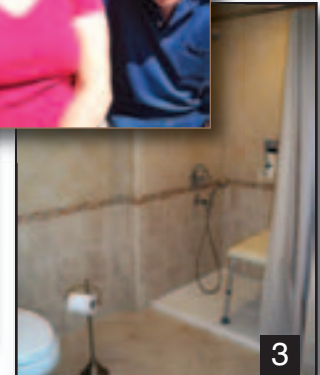
- Don't rush into making changes within the house - wait a bit to see what will serve you best.
- Be patient with the kids -- it takes time for them to learn to pitch in--but with guidance they get it.

Feeling secure at home, Carol looks forward to finding equal accessibility when she ventures out. "We miss Atlantic City and also going out to visit relatives and friends!" Carol explained while whipping up a cheesecake. Still, she says, accessibility does not guarantee unencumbered access. "I always call ahead, always. I remember being sent by disability to a doctor and his office was not wheelchair accessible!"

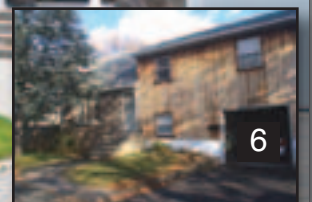
Tenacity exemplified.



**Photos:** 1. Carol's wheelchair-accessible kitchen island  
 2. Tony with granddaughter, Alicia, during construction  
 3. On-suite bathroom 4. Carol preparing for family gathering  
 5. The house now updated 6. The house prior to renovation



Photos: R. Cantwell and Sokol Family





**A+ Editor's Top Choices in great websites, products or resources.**

**BRAIN**

**AEROBICS**



**WEEKLY:** Features fascinating facts, word puzzles, tips/ideas and insights with nostalgic references. Promises to keep you interested and challenged.  
<http://www.wisernow.com>



**NJ SELF-HELP GROUP**

**CLEARINGHOUSE:** Found at [www.selfhelpgroups.org](http://www.selfhelpgroups.org), and run through St. Claire's Health System, this free service has been helping individual caregivers find or form support groups since 1981.  
 Phone 800-367-6274 for info.

**Caregiver's Top 10**

1. **You are not alone.**  
Ask for help. *Access Respite.*
2. **Be an informed consumer.**  
Think before you make important decisions while under stress.
3. **Write everything down!**
4. **Recognize brain overload.**
5. **Be assertive...**  
not aggressive.
6. **Do not assume that**  
directions are followed.
7. **Designate one family**  
member to be the patient's primary advocate.
8. **Practice listening.**
9. **Promote independence**  
*within proper context.*
10. **Work to maintain an**  
individual's dignity.

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## VETERANS' AID AND ATTENDANCE SPECIAL PENSION~

*Often overlooked, this underutilized Veteran's benefit also available to spouses*

The Veterans' Administration offers a Special Pension with Aid and Attendance (A&A) benefit that is largely unknown. This Special Pension (part of the VA Improved Pension program) allows for Veterans and surviving spouses who require the regular attendance of another person to assist in eating, bathing, dressing, undressing or taking care of the needs of nature to receive additional monetary benefits. It also includes individuals who are blind or a patient in a nursing home because of mental or physical incapacity. Assisted care in an assisted living facility also qualifies.

This most important benefit is overlooked by many families with Veterans or surviving spouses who need additional monies to help care for ailing parents or loved ones. This is a "pension benefit" and is not dependent upon service-related injuries for compensation. Most Veterans who are in need of assistance qualify for this pension. Aid and Attendance can help pay for care in the home, nursing home or assisted living facility. A Veteran is eligible for up to \$1,632 per month, while a surviving spouse is eligible for up to \$1,055 per month. A couple is eligible for up to \$1,949 per month.

The Aid and Attendance Benefit is considered to be the third tier of a VA program called Improved Pension. The other two tiers are Basic and Housebound. Each tier has its own level of benefits and qualifications. While the objective of the VeteranAid.org site is to disseminate information about the Aid and Attendance Benefit, we urge you to read an important document prepared by the American Veterans Institute that clearly explains the Improved Pension program, its levels of benefits and the qualifications for each. If you or your loved one do not qualify for Aid and Attendance, you may want to check to see if you qualify for another level of the Pension.

When visiting the site take advantage of the easy to use menu on the left side of the page. It allows you to learn more about the Aid & Attendance Special Pension, Eligibility Requirements, How to Apply, What to Expect and Resources. Each category is there to help you understand this critical benefit. Also, please visit the Sponsors of this site who have made it possible to disseminate this information to veterans and their families.

The One Experience page of the website contains critical information on this application process.



Don't forget to take a look and interact with others in the VeteranAid.org Forums!

We are extremely pleased to announce that VetAssist.org, with the sponsorship of American Veterans Institute, now offers free assistance for Veterans and their families in filing for the Aid and Attendance Special Pension.

Also, please visit American Veterans Institute--a non-profit organization dedicated to honoring Veterans. Responsible for such missions as Operation Welcome Home, AVI is a tremendous resource for Veterans and their families. <http://www.americanveteransinstitute.org>

*This article was contributed by Debbie Burak who started VeteranAid.org in 2005 after the passing of her mother. Debbie fought for her mother's Aid & Attendance Special Pension, which was awarded through her efforts. However, her mother passed before any of the benefits were paid. Frustrated with the entire process of filing for this benefit, Debbie has dedicated her efforts to disseminate information about the Special Pension so that it would become as well known as Social Security. Debbie may be reached at [VetHelp@VeteranAid.org](mailto:VetHelp@VeteranAid.org)*

### ***Having difficulty with your claim?***

**Debbie Burak from VetAid.org states: Asking for an expedited processing of a claim is no guarantee of action. Here are a few tips:**

1. Ask your State Senator or Congressperson for assistance
2. Seek help in completing your application, the form is over 20 pages in length
3. It is illegal to be charged for assistance with filling out the form
4. ALWAYS keep copies. Any correspondence mailed should be return receipt
5. Emergency claims can be given expedited status--but you have to ask
6. Recognize that losing your patience with person on the phone will not help.



**ARE YOU INVOLVED WITH OTHERS WHO NEED ASSISTANCE?**

***YOU JUST MIGHT BE A CAREGIVER!***

*Caregiver events are popping up throughout the country.*

Recognizing a growing need to promote knowledge and sensitivity about caregiver issues, The Caregiver Coalition of Bergen County, (NJ) is taking a pro-active role in assisting caregivers.

In partnership with the Department of Senior Services, the coalition is a caregiver-centric group that meets monthly. New members are welcome.

For more information contact Coordinator of Education and Outreach Linda Cross at (201) 336-7427.

**SAVE THESE DATES!**

**Bergen County, NJ**

Annual Caregivers Conference  
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 October 25 Hamilton Crowne Plaza  
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**Need Help? Start Here.**

Call 2-1-1 or click [www.nj211.org](http://www.nj211.org)  
 Free 24-hour statewide service - putting people in need of assistance, in-touch with people who can help.



NJ 2-1-1 is a system of support using inbound calls as well as a Website ([www.nj211.org](http://www.nj211.org)) with Instant Messaging capability, that is intended to provide free, personal assistance to anyone trying to navigate their way through the vast network of health and human services, government assistance programs and local community resources in New Jersey.

The organization is dedicated to lessening the burden of callers by providing understanding and compassion along with the information that is needed to address the caller's concerns.

This confidential service is supported by United Way in partnership with the State of NJ Department of Human Services, Office of Homeland Security and Preparedness, Department of Health and Senior Service, and the Department of Children and Families.

NJ 2-1-1 Partnership provides free and confidential information and referral. The NJ 2-1-1 database that has over 12,000 programs and services that will help callers gain access to existing resources for life's toughest challenges and everyday concerns. The call staff is available (and accessible simply by dialing 2-1-1) at any time of the day or night. The service is free and confidential. This same database is available online.

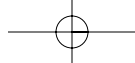
Call 2-1-1 for help with food, housing, employment, health care, counseling and more.

**Need Respite?**

Find respite in your community with this free service at [www.respitelocator.org](http://www.respitelocator.org)



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[www.archrespite.org](http://www.archrespite.org)



## While you are at work...

*Will she remember to turn off the stove?  
Can I take off for his next doctor's appointment?  
It's time for his medication--Should I call to remind him?  
I have to get her into the tub tonight, how will I manage?*

## Where are your thoughts?

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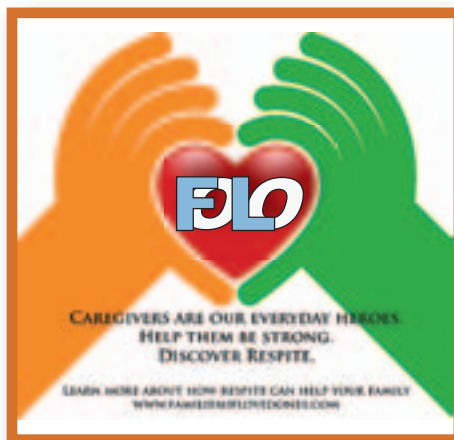
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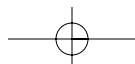
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# COMPASSION FATIGUE

Recognizing and Managing Compassion Fatigue: A Path to Wellness

**CAN WE  
BURN  
OUT?**

Within the past ten years, the secrets to recognizing and managing Compassion Fatigue trickled down from academia to those of us in the caregiving professions. Thanks to the work of leading traumatologists and psychologists, we now share a comprehensive knowledge of the secondary traumatic stress that plagues caregivers worldwide. As more information becomes available, we better understand what is necessary to alleviate the suffering that Compassion Fatigue causes in our lives. *In turn, we help ourselves so we can continue to help others.*

With focused attention on creating good health, we embrace new ways to approach self-care. As an understanding of our destructive patterns unfolds, we begin to see how these behaviors affect our ability to provide healthy caregiving to others. *Symptoms such as isolation, emotional outbursts, substance abuse and health-depleting addictions rob us of our well-being.* Accepting and naming these symptoms is the first step toward healing. Pinpointing their origin, which often involves stepping back in time to explore faulty perceptions, can be daunting and painful. But to forgive our past and accept the role it plays in our present actions delivers us on the doorstep of emotional and physical healing.

Once we suffer from Compassion Fatigue, it is always with us. We must be diligent about managing its symptoms. Compassion Fatigue waits in the wings for us to revert back to unhealthy thoughts and actions and then surfaces once again. Managing the symptoms successfully takes commitment and resiliency.

*Practicing healthy coping skills such as physical exercise, meditation, yoga, or walking Fido is mandatory.* Since our ways of coping are as unique as we are, the work involved is well worth the effort. For the most part, those of us who suffer from Compassion Fatigue are "other-directed." We place the needs of others before our own needs. The work before us is to become acquainted with ourselves - our likes, dislikes, strengths and shortcomings.

Every day on the Compassion Fatigue Awareness Project© website, I hear from caregivers who have experienced Compassion Fatigue and have traveled the path leading to self-acquaintance. Now, it is important to them to pass their knowledge on to oth-

ers. As trainers, they experience satisfaction in sharing their success story with other caregivers. They enter their workshops armed with the latest findings on the signs and causes of Compassion Fatigue, and also how to alleviate the disturbing symptoms.

Encouraging their participants to disregard old destructive patterns, they educate them as to how to create a healthier lifestyle.

The road to wellness begins with one step—awareness. Once we accept that Compassion Fatigue is real and harbors the ability to sap our energy and passion for life, we can reverse the process.

By embracing authentic, sustainable self-care, we open the door to a better life. And, ultimately, happiness.

*Patricia Smith is the founder and CEO of the Compassion Fatigue Awareness Project©, the outreach division of Healthy Caregiving, LLC. As a certified Compassion Fatigue Specialist with more than 20 years of training experience, she writes, speaks and facilitates workshops in-service of those who care for others. Smith may be reached at [patricia@compassionfatigue.org](mailto:patricia@compassionfatigue.org)*



The basics of Compassion Fatigue may be found at <http://www.compassionfatigue.org>. Visit the site for information on:

- What is Compassion Fatigue?
- What are the symptoms?
- What are the causes?
- What is the Path to Wellness?
- Compassion Fatigue Self-Test

The Compassion Fatigue Self-test is based on the ProQOL R-IV, PROFESSIONAL QUALITY OF LIFE SCALE. The following are a few statements that help guide you through the test.

*I am proud of what I can do.*

*I feel "bogged down" by the system.*

*I can't recall important parts of my work with trauma victims.*

*I am a very sensitive person.*

*I am happy that I chose to do this work.*

## NEW FEATURE CAREGIVERS FORUM

~with Ron Kauffman



### Today's Topic: Recognizing & Dealing with Cognitive Impairment

The good news is that forgetting is a normal part of aging. Things like forgetting where you put your car keys or failing to recall an occasional word or a name are normal occurrences in the aging process. As we age, our brains shrink, and our ability to have names, words and other information at our fingertips may be slowed. It doesn't mean we've forgotten things, usually they come to us, but the retrieval of that information may take longer.

Some early signs of forgetfulness that may not be normal include forgetting things you typically remembered—such as doctor's appointments or your weekly Bridge game—and doing so more than once every now and then. If memory loss becomes more of a pattern, it should be a red flag for the possibility of a cognitive disorder. Memory loss may be due to Depression or an early memory-related problem called Mild Cognitive Impairment (MCI), a memory loss issue that is often a precursor to the development of Alzheimer's disease. Or, it could be the onset of Alzheimer's disease.

Here are a few basic comparisons of serious memory loss versus normal forgetfulness:

**1. Memory loss** -Forgetting recently learned information, or forgetting more often and unable to recall the information later.

*What's normal?* Occasionally forgetting names or appointments.

**2. Difficulty performing familiar tasks** - Struggling to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.

*What's normal?* Occasionally forgetting why you came into a room or what it was you planned to say.

**3. Language Problems** - Forgetting simple words or substituting unusual words, like saying “my ear things” instead of the words “hearing aids.”

*What's normal?* Occasional trouble finding the right word.

**4. Problems with abstract thinking** - Having difficulty performing complex mental tasks like forgetting what numbers are for and how they should be used.

*What's normal?* Finding it challenging to balance a checkbook.

What should you do if you begin noticing that a family member has begun to show signs of being more than "normally" forgetful? Here are four ideas: (1) Don't assume that your loved one's forgetting is normal. (2) Begin making notes of some of the incidences of forgetfulness so you can later recount them when meeting with a physician. (3) Suggest to your loved one that seeing a professional may be helpful in improving his/her memory. (4) I recommend you see either a geriatric physician or a neurologist who works with memory loss issues. You'll get a professional assessment of the problem and receive a definitive diagnosis. Knowing if the problem is physical or cognitive is crucial to establishing a plan to deal with whatever it may be. Recognize changes and don't delay taking action. It matters.

If you have questions, please e-mail them to me. Until next time, be well and thanks for caring.

*Ron Kauffman is a Certified Senior Advisor and an expert on issues of aging and caregiving. He is the author of Caring for a Loved One with Alzheimer's Disease, available at [www.seniorlifestyles.net](http://www.seniorlifestyles.net). He can be reached by e-mail at [drron407@bellsouth.net](mailto:drron407@bellsouth.net), or by telephone at 561-626-4481.*



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## The New Jersey Personal Preference Program (PPP)

New Jersey's Personal Preference Program is a "**cash & counseling**" program that offers an alternative way in which Medicaid recipients may receive **Personal Care Assistant (PCA)** services. What makes this program unique is that instead of receiving PCA services through an agency, participants may direct their own services. With this flexibility, participants hire whomever they choose, *including family members and friends*, to assist them with a variety of personal care needs. Participants also can purchase goods and services which meet personal care needs under the program.

Personal Preference offers choice and personal control, along with increased responsibility. Each participant is matched with a trained counselor. Counselors do not serve as case managers but more as guides to help participants understand and navigate effectively using the program. Counselors teach participants how to develop a **Cash Management Plan (CMP)**. The CMP is an individualized budget that details the types and costs of services the participant is purchasing. Participants may select a non-paid representative to assist them with their responsibilities if they wish.

Since participants hire whomever they choose, the participant becomes the legal "employer of record." New Jersey uses a service, known as the **Fiscal Employer Agent (FEA)**, to act as the business agent for participants. The FEA manages the program's financial aspects, including processing payroll, to assist participants in fulfilling their employer responsibilities and payment of their taxes.

### Participants' comments include:

*"I get better care and attention by being able to choose my own workers."*

*"The program has made a difference in my life because I can manage my schedule according to my needs."*

*"The program has given me hope and a chance in life. It has allowed me to be my own advocate and not have others making my choices and decisions for me."*



**Call for information on Personal Preference:  
1-888-285-3036.**

**Renee Davidson, LSW**  
**Project Manager**  
**Renee.Davidson@dhs.state.nj.us**  
**New Jersey Division of Disability Services**



## Q&A WITH PROJECT MANAGER RENEE DAVIDSON, LSW

**Q. So to be clear: money that was once used in the Medicaid system to pay for the care, and items for the care of the participant, may now be controlled in use by the recipient?**

**A. Yes. Essentially, we cash out the Medicaid recipient's Personal Care Services (PCA). Instead of Medicaid reimbursing an agency for sending an aid to assist with activities of daily living, those funds are transferred into PPP so that the participant can manage their own services. Instead of just being able to hire workers, they can also purchase goods and services that are directly related to activities of daily living as long as they are not already covered by some other Medicaid benefit.**

**Q. I see that the FEA takes care of paying the caregiver. Are they paid as independent contractors?**

**A. There are no independent contractors in PPP. All participants have registered businesses in NJ and Employer Identification Numbers issued by the IRS. The FEA is responsible for withholding taxes and filing for participants.**

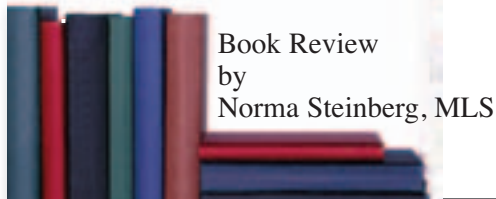
**Q. You mention that items may be purchased. Is there a list of approved and non--approved items? Can you give me examples of each? Does the client need to spend the cash and wait for reimbursement or is there a "card" available for this use?**

**A. We have a list of approvable and non-approvable items. All items must be requested on their cash management plan. They are not automatically approved just because the item/service may be on the list. The participant must be able to prove that the item/service is directly and clearly related to meeting a personal care need. For example, if someone needs assistance with meal preparation and they want their worker to prepare meals ahead of time and store them in the refrigerator/freezer, they can request to purchase a microwave so that they can easily heat their meals when their worker leaves for the day. A Washer or Dryer is another good example. If a participant is sending his worker to the Laundromat for 4 hours every week, they may choose to save money to buy their own washer and dryer. Again, the item needs to be requested in the CMP. There is a section of the CMP that allows for participants to save for big-ticket items over a long period of time. If the washer and dryer cost \$1000, they could save \$100/month which allows them to purchase the washer/dryer in 10 months. After purchasing the washer/dryer, the worker will be able to attend to other tasks while the laundry is being run, or the participant may even be able to do some of his own laundry.**

**Q. And finally, do you know of similar programs in other states, and are these funds available now?**

**A. NJ was one of the 3 original states, along with Florida & Arkansas, in the National Cash and Counseling Demonstration Project. Since then other states have developed their own similar programs. ~RC**

## ... The Bookshelf



### RELEASED TO THE ANGELS *A Caregiver's Journey*

by Marilyn Garzione  
167pp, 2009  
\$16.95  
ISBN: 978-0-595-50632-3  
Indiana, iUniverse  
Publisher,  
Paperback

*"This morning I washed his hair at the kitchen sink. Then I brought him to the bathroom mirror and handed him his comb. I came back some minutes later to see him standing quietly, staring at himself in the mirror. It must have been one of those rare moments that he looked at his appearance. Patrick has kept his dark hair all these years, and although it has thinned somewhat with the passage of time, there are only a few strands of gray above, accented by more silver in his beard. He turned to me and with trusting innocence asked, 'Can you get me some more hair?'"*

*"God granted us memory so that we might have roses in December."*  
--J.M. Barrie, 1922

Marilynn Garzione, in this slim volume of only 167 pages, holds your hand and gently guides you through the progressive stages of Alzheimer's Disease both from the patient and the caregiver's point of view.

The book is presented in 138 vignettes, each no longer than 2 pages. In a heartfelt and deeply moving manner, the author delivers poignant scenes from her family's incredible journey and highlights authentic accounts of what to expect as the disease progresses.

Garzione educates and cradles the reader in the most loving manner, dividing her material into three stages of development—The Early stages: It Begins; The Middle stages: Living in the Now; and the Advanced stage: Letting Go.



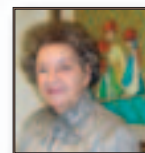
Experiencing the loss of both her husband and her father to this dreaded disease has inspired Garzione to write this honest and compassionate volume and to be an advocate for Alzheimer's awareness and research.

More than five million Americans currently live with the disease. It is her hope that her book will provide support to those families. She is the only author I have ever read who gives her personal telephone number and invites the reader to "Call anytime."

Marilynn Garzione is a recipient of "The Editors Choice Award" and is recognized as a "must read" by the Alzheimer's Association. Her Masters Degree was obtained at the Middlebury College in Vermont. Garzione has lived in Puerto Rico and Spain, and currently teaches at the New York State University at New Paltz, New York. She has written numerous articles for publications in the field of education. For more information visit [www.releasedtotheangels.com](http://www.releasedtotheangels.com).



*Steinberg is a retired librarian from the Grand Army Plaza branch of the Brooklyn Public Library.*



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## The Caregiver Compassion Quotient: WHAT'S YOUR CQ?

*The higher your CQ, the better you feel.*

*Fill yourself up with Compassion: your energy will increase.*

**CQ** eases caregiver turmoil  
(*mental.*)

It helps dissolve stress  
(*emotional.*)

It makes the hapless unending  
work load seem lighter  
(*physical.*)

And there's more.

You're choosing a smoother,  
healthier life.

**CQ** is your sigh of relief.

It's the spiritual component  
that offers you an art  
you can practice.

How can you raise your **CQ**?

Tip your scales in favor of what  
strengthens your spirit.

Your compassion *IS* your spirit.

This very instant—and every  
worst moment—

**Become a Loving Presence.**

What we humans crave is to be  
loved, in spite of ourselves.

Keep picturing, keep thinking  
about the most compassionate  
care you can provide.

It's the highest thought there  
is—truly Divine.

- Excerpted from LESSONS IN THE DIVINE FOR CAREGIVERS

Author ~ P. M. Kearns

LESSONS IN THE DIVINE FOR CAREGIVERS is available through [www.iUniverse.com](http://www.iUniverse.com) and fine booksellers. For more about P.M. Kearns and The Caregiver Compassion Quotient, visit [www.caregiving.com](http://www.caregiving.com). Enjoy her articles on J&J's website, [www.strengthforcaring.com](http://www.strengthforcaring.com), and at [www.discovernursing.com](http://www.discovernursing.com).

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### AUTUMN ISSUE PREVIEW

#### "The Reluctant Caregiver"

Shannon Martin, M.S.W., CMC, explores the mixed emotions that may accompany taking on the role of caregiver.

#### Therapeutic Recreation (TR):

William Wright, CTRS gives us an indepth view on the benefits of professional TR.

#### Relieve Stress by Journaling:

B. Lynn Goodwin's experience as caregiver, teacher and writer helped her to find comfort in journaling. She asserts you can too!

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# Effective Communication and Protecting Privacy

## HIPAA Releases - What you Need to Know

### What is HIPAA?

HIPAA is the affectionate acronym for the *Health Insurance Portability and Accountability Act of 1996*. HIPAA protects your rights to your medical info, "Protected Health Information," or PHI for short. HIPAA assures you access to your medical information, while simultaneously preventing others from obtaining it. These rules have broad implications to a wide range of personal and estate transactions.

### Why It's So Important

Addressing HIPAA, and how your medical info should be disclosed, are vitally important. If you're ill, can your daughter get to see your patient chart to monitor your care?

### HIPAA Authorizations

A medical provider cannot disclose your Protected Health Information (PHI) without your authorization. Exceptions are provided that permit disclosure for treatment, payment, and health care operations. You, as a patient, have the right to authorize the release of your PHI. Someone who qualifies as your HIPAA personal representative can also authorize the release of your PHI. There are a number of specific requirements to address to make such an authorization valid.

- **Writing:** The authorization should be in writing.
- **What:** It should describe the health information to be disclosed. This could be your entire medical record, or only specified components. You might specify that your medical records between certain dates be released.
- **Who:** Which medical provider should make the disclosure? This could be a specific physician, hospital or a list of providers.
- **Term:** When does the authorization to disclose PHI expire? This could be: "upon a child attaining age 21." It could be "2 years from the signing of the authorization."
- **Revocation:** A statement that you retain the right to revoke any authorization to disclose your PHI.
- **Re-Disclosure:** The release may state that certain information, such as HIV testing results, cannot be disclosed by the person receiving it.
- **Purpose:** Explain the purpose for the disclosure.

- **Signer:** If you are signing the authorization, the signature line should merely state that you are the patient. If another person is signing for you, the authorization should state that this person qualifies as your personal representative under HIPAA.

For additional information on HIPAA privacy, including how to file a complaint, see the U.S. Department of Health & Human Services website at [www.hhs.gov](http://www.hhs.gov).

*Martin M. Shenkman, CPA, MBA, JD is a prolific author, having published over thirty five books and more than seven hundred articles. His practice concentrates on estate planning and administration, tax planning, and corporate law. Specializing in empowering people through his writing, he is regularly sought out as an expert in estate law by media outlets including The Wall Street Journal. He has an active legal practice in New York City, publishes a regular newsletter called the Practical Planner. He was named one of Worth magazine's 100 top attorneys in 2007, as one of the top 40 accountants by CPA Magazine in 2008 and 2009. His recent books include **Estate Planning for People with Chronic Illness and Disabilities (Demos)**; **Estate and Related Planning During Economic Turmoil (AICPA)** and **Life Cycle Planning for the CPA Practice (AICPA)**, **The Complete Book of Trusts (Wiley)**, and others. He earned a BS in economics - Wharton, MBA - University of Michigan, law degree - Fordham University, and is admitted to the bar in New York, New Jersey, and Washington, D.C. He is a CPA in New Jersey, Michigan, and New York and may be contacted through his Tenafly, New Jersey office at 201-845-8400 or his website [www.laweasy.com](http://www.laweasy.com).*



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IN MEMORIAM

## Observations and Insights~A son looks back

by Kenneth Chan

Dad lived a vibrant and independent life. He traveled internationally, but ultimately immigrated to the United States. A New Yorker and active Christian, he always sought to improve himself and do things for others. He was a photographer and helped with our family business.



When he began to experience Parkinsonian symptoms and early dementia, his life of independence transitioned. The man who usually did things quietly for others now needed assistance for himself.

Together there were the visits to the doctors and attending support group meetings. As a family we accepted the challenges, and grew together to confront managing the time required in going to these events, and the frustration of knowing life wasn't the way it once was.

For some time we were able to adapt to Dad's Parkinsonism, and to continue with life as best we knew it. However, Dad suffered a stroke a good number of years after and his condition progressed. We could no longer take care of him ourselves.

We would spend hours with him, loving him and making sure he was taken care of properly to best improve his condition. Mom meticulously attended to his daily needs, and as a result he lived some years in nursing care while roommate after roommate came and passed. Her familiarity with nursing staff and care increased; she became his advocate. Dad ultimately suffered complications from an ill-explained transportation event, and survived only a few months after.

Reflecting over the past years I have no regrets of the hours just being with Dad, and making sure that things were done correctly for his well being. After all, what wouldn't you do for someone you love?

Our way of showing that love was to make sure that he was being taken care of properly, that the opportunity for him to improve was there, and that he knew we were there for him.

In so many ways, even in his state of disability, my father continued to teach and show his love to both my mother and me.



Kenneth and Amy Chan are generous supporters of FOLO

## Non-Profits in Action

### CaringBridge: A Lifeline for Patients and Families

Families unprepared for a loved one's health diagnosis can be overwhelmed by medical terminology, treatment decisions and hospital visits. It's times like these that families need support from extended family and friends. But even trying to respond (much less reaching out) to them using the phone or personal e-mails is overwhelming and exhausting. CaringBridge was created to help these families receive support and provide information, while increasing time available for patients and their caregivers. Individual CaringBridge sites can be an important tool for families dealing with the stress of a health situation, giving them an appropriate outlet for sharing their feelings and receiving support.



CaringBridge provides free personal and private websites to patients and families when someone is facing a serious health event. The site provides a place for users to post journal entries and photos, as well as receive messages of hope and encouragement in a guestbook. Centralizing communication saves time and energy. Everyone can stay in touch, regardless of time zones and area codes.

Maureen Anderson of North Oaks, Minnesota, set up a site for her husband.

*"I sent his CaringBridge website link to a few family members and friends, and it just mushroomed! Suddenly I was flooded with support and caring messages. In no time, friends I hadn't had time to contact were bringing over food, or even snow-blowing my driveway. It was as if an umbrella of caring, support and love had suddenly enveloped us."*

For more information, visit  
[www.CaringBridge.org](http://www.CaringBridge.org).  
 Melissa Holm  
 651.789.3375  
[media@caringbridge.org](mailto:media@caringbridge.org)





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