

\*\*\*COMPLIMENTARY ISSUE\*\*\*



# MAINSTAY

**Well Spouse® Association**  
*Support for Spousal Caregivers — You Are Not Alone*

## DATELINES:

Log on to the WSA website for the latest news on upcoming events...

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

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## The Caregiver Journey

*Pathways to an authentic and fulfilling life*

*By Marty Beilin*

Shock dulls the senses. In all our lives that moment came when a doctor spoke words that let us know an accident or illness or stroke had forever changed the life of our beloved partner. It probably took several days or even many weeks for the scope of the disability and prognosis to sink in. What would take longer for our mind to grasp, often much longer— months and years – is how and the extent to which our lives, too, would be transformed. The fear, anger, and despair no doubt felt at times by our ill/disabled spouse would wash over us as well.



A few years ago I wrote in *Mainstay*, “Membership in Well Spouse® cannot make us whole again. But this association of spousal caregivers can help us confront the realities of our lives with hope, not resignation.” But how? It is so easy to become overwhelmed by the stress of long-term caregiving. Even the most buoyant personality surely must be weighed down witnessing one’s mate’s progressive loss of health, function, and mobility. Where is the hope?

Sharing our stories helps well spouses connect with each other and lessens anxiety. There is comfort in knowing that I am not alone – That others have gone down this road before... and survived!

But the Well Spouse® Association’s mission is not simply to help spousal caregivers just cope with their difficult situation. While the empathy generated by sharing personal stories is valuable in and of itself, our aim should be to create for ourselves nothing less than an “authentic life” --

*(continued on page 3)*

## Well Spouse® Member Benefits

Quarterly Newsletter  
*Mainstay*  
Bi-weekly E-newsletter  
*Member Minute*  
Support Groups and  
State Contacts

WSA website-  
Forum  
Support Group listings  
Important Info and  
Updates  
Important Links  
On-line  
membership/renewal  
On-line donations  
Caregiver Bill of Rights  
Mentorship Program  
Annual National  
Conference  
Regional Respite  
Weekends  
Caregiver Journey  
Workshops

\*Fellowship, long  
lasting friendships and  
the feeling you get in  
knowing our motto

*You are not alone.*

### WSA Membership AND Annual Appeal

*WSA's mission to  
provide emotional  
support to  
spousal caregivers is  
funded primarily by  
membership dues and  
our Annual Appeal.*

*We welcome supporting  
memberships from  
professionals and  
organizations who would  
like to regularly receive  
our newsletter,  
Mainstay, brochures,  
and other information to  
pass along to their  
clients.*

## WHO WE ARE... WHAT WE DO.

The Well Spouse® Association is dedicated to the support of wives, husbands, and partners of the chronically ill or disabled.

WSA is the only national organization focusing exclusively on the challenges and issues facing spousal caregivers. We have over 1400 dues paying members.

The founding “well spouses” gained their inspiration from Maggie Strong’s book, *Mainstay: for the Well Spouse of the Chronically Ill*, first published in 1988.

The Well Spouse® Association is incorporated in the State of Delaware as a non-profit 501(c) (3) corporation.

We coordinate a **Mentorship Program** matching new caregivers with “veteran” well spouses.

We coordinate a **National Network of Support Groups and Contacts**, and we assist well spouses who wish to organize new local support groups where none currently exist.

We publish and mail **Mainstay**, our **quarterly newsletter**, and email **Member Minutes**, our e-newsletter every two weeks.

Our **website (www.wellspouse.org)** contains the latest announcements, articles of interest, links to other caregiving sites, a directory of Well Spouse® support groups and Contacts as well as professional and corporate partners. Also offered is an online Forum, where members can share their thoughts, feelings, and support each other.

We help local groups organize **Regional Respite Weekends** for spousal caregivers.

We organize and host an **Annual National Conference**.

Letters of support and friendship are circulated among “circles” of spousal caregivers through the Well Spouse® **Round Robin letter-writing group**.

We seek ways to partner with other organizations such as the National Multiple Sclerosis Society, Medtronic, National Family Caregivers Association, National Alliance for Caregiving, as well as private corporations, to promote activities or publications that will benefit family caregivers.

WSA is a volunteer-based organization. We rely on membership dues and donations, grants and contributions from private businesses and other charitable organizations to cover our operating expenses. Annual dues are \$30 a year. Reduced fee membership is offered to any spousal caregiver who cannot afford the annual dues.

*When one is sick...two need help*

(continued from page 1)

one not defined solely or even in the greater part by our spouse's medical condition. In any healthy marriage or committed relationship, it is important that each partner take time to pursue his own interests and give expression to her talents and dreams. This should be true in a marriage where one spouse is ill. While we all want to be excellent caregivers for our partners, to provide good care we must first care for ourselves. To neglect our own well-being is to risk burnout... and then we serve neither our partners nor ourselves very well.

In her inspirational book, *Mainstay*, Maggie Strong suggested that three stages typified a caregiver's life. This "caregiver journey" can serve as a powerful metaphor for how we can re-center our lives.

### **The Heroic Stage**

The diagnosis is in, and a "productive panic" energizes you and family members. You want to learn as much as you can about your spouse's illness or disability. Doctors and other experts are consulted. You read everything you can on the subject. You receive encouragement from family and co-workers - even offers of help.

Optimism often characterizes the heroic stage. You will help your spouse heal, recover, walk, get well.

Often there is improvement; sometimes even complete recovery. But over time when there is little improvement or decline, hope slowly fades and optimism turns to despair. Friends and family members may drift away. Help now is most likely provided by paid aides. Denial may keep the caregiving spouse working towards a "cure" that is not possible. The heroic stage comes to an end as you come to terms with the reality of your spouse's condition and prognosis.

**To neglect our own well-being is to risk burnout... and then we neither serve our partners or ourselves very well.**

### **Ambivalence**

Long-term caregiving sets up debilitating internal conflicts. On the one hand, you want to support and care for your partner. It's the right and moral thing to do. You are motivated by love, or a sense of duty, or societal expectations. At the same time you feel physically exhausted. Financial concerns mount. You may have to quit your job. Intimacy is difficult or impossible. You don't see a future. You want to get out.

The ambivalence stage of the caregiver journey postmarks the landscape with intermittent (or, in many cases, constant) feelings of fear, anger, sadness and resentment. Many caregivers need medication to manage clinical depression. To avoid caregiver burnout, caregivers will devise ways to compartmentalize their lives. But stress commonly undermines the best coping strategies. While instability is a hallmark of this stage, sadly for caregivers, the ambivalence stage can last for quite a long period of time. This stage comes to an end when the instability becomes so untenable that one suffers total burnout or, much more positively, the caregiver commits to a desire to go beyond coping and make real changes in her or his life and approach to caregiving and the marital relationship itself.

### **The "New Normal"**

In this stage, balance, resolution, and inspiration empower caregivers to live much more fulfilling lives. You recognize and come to terms with the long-term nature of your situation. But you don't put aside your desire to pursue your own interests and dreams.

To achieve balance, you communicate more openly with your spouse and take steps needed to resolve the often difficult and painful issues in the marital relationship. You engage your spouse in ways that preserve activities that you both enjoy and seek new ways to share time together. Or, you decide that, no matter how painful, the best way you can support your partner is by separating. Separation can take many forms: placement in a

nursing home or adult daycare, divorce, or informal, separate living arrangements. Whether living together or apart, you commit to caring for your spouse, providing both financial and emotional support to the best of your ability.

Support is essential to achieving and sustaining this “new normal” stage in one’s life. Many well spouses have placed faith and prayer at the center of their lives. Whether formal religious practice or personal and more secular-based **spirituality**, faith in a higher power not only provides comfort in times of crisis, faith can also imbue one’s life with meaning and purpose.

**Professional counseling and medication** can support well spouses in the choices they make.

Finding ways to increase in-home care may allow well spouses to live a “new normal” life.

Organized support groups such as those sponsored by the Well Spouse® Association keep spousal caregivers from becoming isolated. WSA support group members offer not only practical information, but also provide emotional support. Support groups can also create respite opportunities needed to relieve the stress of daily caregiving routines.

The “new normal” is achieved when we no longer go about our caregiving responsibilities with resentment but attend to the needs of our partner with love.

*Finding one’s way...*

The caregiver journey is a progressive undertaking. It is not an easy journey. We often refuse to come to terms with our “new reality” and stay too long in the heroic stage. Or we become mired in the ambivalence stage of the journey. And even when we pass from one stage to the next, it is quite common to revisit a stage we thought we had passed through. “Two steps forward, one step back.” Achieving a “new normal” is not guaranteed.

Helping well spouses understand these stages of the caregiver journey and encouraging our members to find their own pathway to the “new normal” is, then, the main mission of the Well

Spouse® Association. The losses we have experienced as a result of chronic illness and disability are very real. We will never be made whole in the way we had hoped. We can - and should - find satisfaction in our caregiving and make caregiving a part of who we are, but not all that we are.

*Now it’s your turn...*

*Whether yours is a spiritual or religious awakening, a practical idea, a humor-filled moment, or a serious reflection, we want to hear from you. We welcome your submissions —*

*Personal Story – Poetry - Caregiver Tips - Artwork  
Travel Story - Spiritual Journey – Humor - Book reviews*

EMAIL: [mainstay@wellspouse.org](mailto:mainstay@wellspouse.org)

MAIL: WSA-Mainstay, 63 West Main St., Suite H,  
Freehold, NJ 07728

## **Help WSA raise money every time you search the web or shop online!**

Raise a penny for our organization every time you search the web! **iSearchiGive.com** is a new search engine powered by Yahoo.

**iGive.com** is the internet’s first online shopping mall with 700+ online stores where a portion of each purchase is donated to your favorite cause. Create your free iGive account today and start helping every time you shop while getting exclusive coupons and deals

Totally free – No hidden fees – No limits  
Monthly Donation Checks to WSA

### **KNOW A DISABLED VETERAN?**

If you are caring for a veteran or if you know anyone in your area, have them contact either the office or Larry Bocchiere -- **[larry@wellspouse.org](mailto:larry@wellspouse.org)** -- and we will start their free one-year membership. We are having difficulty in spreading the word of this through official channels, so if you have any contacts at local Veteran Administration facilities please let them know, or contact Larry and he will send a letter and brochures.

# Caring for the Caregivers

WSA –

*A reminder of who we are and what we do.*

By Dorothy Pocinki

**T**he members of the Well Spouse® Association are dedicated to helping one another because we are the only international support group (USA and Canada) whose focus is the support of spousal caregivers, people whose lives are devoted to caring for their chronically ill or permanently disabled spouses.

Our members range in age from those in their twenties to many past seventy. Many of us work full time, if we have been fortunate enough to find competent help at home, in the belief that pursuing our professional careers enables us to continue to exist as vital, informed individuals, apart from our caregiving responsibilities, even though most of the money we earn must go to pay health aides.

The Well Spouse® Association includes a significant number of former well spouses, members who have lost their spouses but remain affiliated with the organization because of the emotional support they received and the caring that sustained them when they desperately needed help.

Some of our members care for quadriplegics, victims of random shootings or horrible accidents. They also have children to nurture and a household to maintain. The dirty details of such caring we will leave to you to imagine. Those whose spouses suffer from long-term debilitating illnesses like MS, Parkinson's disease or the early stages of Alzheimer's, may have young teens at home, embarrassed by their father or mother's inability to walk properly, their tremors, or their frequent difficulty in expressing themselves clearly.

In some cases the parents of the ill spouse, often in a state of denial about their son's or daughter's illness/disability, refuse to visit or offer any help, emotional or financial, to the caregiver, preferring to believe that the primary burden of caregiving must be on the person their child chose to marry.

The support groups of the Well Spouse® Association, approximately 60 of them, with more forming each month, are the heart of the organization. Some

members who do not live near a support group stay in touch through Round Robin letters. Many members, however, living in an area where no support group exists stay in touch by means of our website – where they chat, exchange caregiving ideas, get information about future respite weekends and read about plans for other activities like our annual conference, held each October to help members meet, chat, exchange ideas, laugh and even dance. Meeting other well spouses face to face, members bond almost immediately because they realize they do not have to explain what their lives are like. We all understand. We've been there.

Workshops that help to clarify present problems or suggestions as to how to adapt to future difficulties are essential components of such meetings. But relaxation techniques and humor are also built into the conference schedules so that those who attend truly enjoy the experience. We also make an effort to arrange modestly priced outings for our members. The freedom from everyday responsibilities that such occasions provide is invaluable.

Support is also provided through *Mainstay*, our quarterly newsletter written mostly by well spouses.

Henry David Thoreau might have been describing the lives of spousal caregivers when he wrote in *WALDEN*, "Most men lead lives of quiet desperation." We would add, of course, "and women." We turn to one another in times of crisis to pour out our hearts, even weep, knowing that we will be soothed and supported by the words and hugs of our well spouse friends.

On a personal note, my dearest and closest friends are members of the support group I lead in the region covering the District of Columbia and the adjoining suburbs of Maryland. The Board of Directors of WSA that I am privileged to serve with is comprised of a remarkable group of individuals, some of whom are former Well Spouses, and many who are still caregiving. Their selfless devotion to this organization is, in my opinion, unparalleled and is surely one of the main reasons why the WSA has continued to thrive.

(This article first appeared in its original form in the fall 2005 issue of the Healthcare and Aging Newsletter of the American Society on Aging)

## CLEVELAND OR BUST!

*By Melanie Holzberg*

“Norm, get up! It is 6:00 AM and Melanie says you are going out today.” Norm’s nurse started bustling around the room, getting ready for the morning routine. “She says it is a surprise and you have to get ready now.” Norm smiled, sleepy and confused, but always ready to go out.

As a 50<sup>th</sup> birthday surprise for my husband, I had decided to take him to the Rock and Roll Hall of Fame. Now, this was the equivalent of taking a terminally ill child to Disney World. It was his dream for years to travel there, but being paralyzed and dependent on life support put a bit of a crimp in his style. And traveling via air was out of the question in my opinion. There was no way I could handle that!

It was a spur of the moment decision on my part. I had a vacation scheduled from work, with no particular plans other than the usual summer relaxation stuff. Friends had visited Cleveland a few weeks before and brought some souvenirs for us from the Rock and Roll Hall of Fame. It was apparent that Norm was delighted. I started to think about why we couldn’t go ourselves.

With his doctor’s blessing, I began to organize a secret trip from NJ to Ohio. This was no small feat, requiring coordinating nurses, wheelchairs, ventilators, supplies, medicines, oxygen, suction machines, chargers, and internal feeding supplies, among other things. First, I called the Embassy Suites in downtown Cleveland and reserved two suites with two beds in each room and passes for the Rock and Roll Hall of Fame. I asked two nurses if they wanted to come, alternating shifts so that Norm had coverage 24 hours a day. They were eager to accompany us on our adventure. Everything was cleared with the nursing agency, and our 20-year-old son Scott happily agreed to come along. The respiratory therapist gave us the name of a respiratory care company in Cleveland that he knew, who was standing by in case of emergency. We also had the name of a pulmonologist whom we could call if we needed a local doctor.

The morning of our journey arrived, and Norm knew something good was up. Another nurse materialized and started swooping up toiletries, medications, clothing, etc. He figured we were staying overnight somewhere and he was thrilled. Other than hospital stays, he had not slept in a different bed than his hospital bed for years. The second nurse did not come in the house while he was getting ready, but instead packed the van as we brought all the STUFF out! There was so much stuff that we had to pack a car to follow the van!

We brought Norm outside and took a picture in front of the van. He did not know that a nurse holding a “Cleveland or Bust” sign was standing behind him. We then took off, not telling Norm where we were going. He was thrilled just to be “breaking loose.” The nurse, in her car, followed behind. As we headed west, he did not dare to hope that his dream was going to be fulfilled. We gave him some Dramamine as he had a tendency to get carsick. Driving through the mountains of Pennsylvania, he began to get suspicious. We stopped every couple of hours for feedings, dressing changes, bathroom breaks, etc. Scott and I shared the driving, and took turns accompanying the nurse, who drove the car in our caravan.

Ten hours later, we pulled up in front of the hotel, and Norm wore the biggest grin imaginable. We settled Norm and the nurses into one suite, and Scott and I took the suite across the hall. The living room had a sofa bed with a thin mattress, so Scott and I donated the mattress from our sofa so Norm could sleep on a double thickness. There was a kitchen, a bathroom, and a bedroom for the off-duty nurse. One nurse asked housekeeping for lots of extra sheets (draw sheets, etc.) They obliged but questioned why we needed so many sheets. The nurse replied, “We are having a toga party!” and shut the door!

A friend of ours had a contact at the Rock and Roll Hall of Fame, and we were greeted like VIPs the next day. They even let us use the offices for feedings, toileting, etc. They could not have been nicer. We spent two full days exploring the history of rock and roll, watching films, using interactive kiosks to get information, reliving Woodstock, Elvis and the Beatles. We listened to music, sang oldies, bought souvenirs, and reminisced. We were so busy that we did not have

time to explore the entire museum. The night before we left for home, Norm reminded me that he had not had a vacation in many years and was so grateful for what I had done for him.

The next day, we sadly left Cleveland and caravanned back to NJ. It was an uneventful 10-hour trip. Life went back to “normal” (and I use that term loosely), but the memories lingered for years. Friends asked afterwards if I was afraid that something terrible would happen while we were away with the respirator, etc. and that I was brave to undertake the vacation. My reply? We prepared well and enjoyed it thoroughly. If something happened to Norm, he would die happy, his dream having been fulfilled. We brought Mohammed to the Mountain.

(This article first appeared in the Summer 2005 issue of *Mainstay*)

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## RECEIPTS

By Anne Keefe

I was looking for the hand massager for Steve, the one his father had given him long before the stroke. He enjoyed the massage I had given him, but my hands aren't strong and they tire easily. I had just about turned the whole house upside down looking for that massager - when I came across an old cigar box of his. Oh, how he loved those cigars! I opened it expecting to find it empty now that Steve no longer smokes. Instead, crumpled up on top of some computer disks, were old receipts from bank deposits, grocery and liquor stores, the cable company and even a sports store. Intrigued, I smoothed them out one by one and noticed they were all dated a month or so before the stroke. Some of the print was so faded that they were hard to read.

I thought about my dear husband's last moments as a free man — able to walk, talk and work — just going about the ordinary pleasures of daily life not knowing what was about to hit him, enjoying buying a bottle of wine, picking up some last minute groceries, paying a cable bill. Then the last one I turned over just about broke my heart. It was the purchase of a new bathing suit and

goggles for the swimming he enjoyed so much over the last year. An immense sadness washed over me. How the discovery of some old crumpled up store receipts could evoke such nostalgia and pain.

My first inclination was to throw all these receipts out — of what use are they to me or us now, except as bitter reminders of another place and time when all was so different. Yet, something urged me to hold onto them, so I carefully folded and stacked them, put them back in the box, and closed the lid.

I eventually found the hand massager.

*Written as a journal entry, 12/27/04*

*Note: I am now a full time caregiver for Steve. I went from a full time social worker to part time. It's all I can handle. Steve suffered a massive stroke 3 years ago which radically changed our lives. He was left with a paralyzed right arm, hand, and leg, and has chronic spasticity on the right side. Although he spends a lot of time in a wheelchair, he can walk short distances with a leg brace and quad cane when he's motivated. He also has aphasia. In his case, it means he cannot read or write anymore, and can barely put two words together. But the worst is his severe depression since the stroke. – A. Keefe*

### Postings – An On-Line Discussion

Looking for support? No support group in your area? Are you more comfortable using on-line support services? Look to [www.wellspouse.org](http://www.wellspouse.org) for our on-line forum for adults.

You can try out the forum before registering as a regular user. This trial registration is at no cost and is separate from your WSA membership.

Topics discussed include ...

**Help and Healing**

**Specific Illness and Disabilities**

**Parenting and Family**

**Getting Together**—support groups, national and local events, etc.

**Well Spouses Are People Too!**

**Intimacy and Personal Issues**

**Former Well Spouses**

**Resources**

## The Well Spouses I Know

By Gail Mooers

Thirteen years ago I read a book. It changed my life. I wrote a short note and said that I would be interested in being in a support group for persons with chronically ill spouses. A short time later a reply found its way to my mailbox. “Start a group.” Maggie Strong planted a seed. It struggled to grow, with no help from me, was stunted numerous times but in a year’s time took root. As the anniversary of that tiny seed draws near, and at the closing of yet another meeting, I feel the need to reflect on what has taken place in the last 12 years and approximately 200+ meetings.

The people that have come into my life because I am a well spouse are people of substance. This is the best way that I can describe them. All of these years I have been working full time in the “real” world, raising two children, being a well spouse. I have met a lot of people but very few of “substance”. Within our group we have shared tears, raised children, buried spouses, seen members move on with their lives and welcomed new members. We struggle with religion, morals, values, politics, food, drugs, violence, having fun or the lack thereof, not to mention intimacy.

The capacity of understanding, empathy, sharing, listening is phenomenal with these dear people. I look at the careworn faces of the well spouses around me and think of all that they have been through with me - and I them. Judgments happen seldom - except when one of us is not taking care of ourselves and then we do all tend to “gang up” and force some issues.

These people are so full of love. Being a well spouse would not be a struggle if love were not involved. I have come away so often filled with wonder at the tenacity of the human spirit from the compassion shown for each other and for spouses. The cumulative years of caregiving are staggering. Amazingly, so much has been accomplished

without help from agencies, family, or hired staff. We talk of caring. We talk of love. We talk of loss. They mentor, suggest, and support.

I have been blessed being a well spouse. This is the good that comes from a bad situation. Although the sadness sometimes is overwhelming and the loneliness all-consuming, these people have substance. They struggle with life. They wrestle with life’s meaning. They are my friends, my mentors, my comedians, and my support. These are people I am glad to know. I celebrate my 12 years of group facilitating and Maggie Strong planting a seed that has made me a “person of substance”.

(This article first appeared in the Fall/Winter 2004 issue of *Mainstay*)

### Looking for a Support Group in your area?

Visit [www.wellspouse.org](http://www.wellspouse.org) to view a complete, up-to-date listing of our support groups.

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### WANTED!

#### Support Group Leaders

Support groups are one of the main ways we can help ourselves. Serving as a group leader is a truly rewarding experience. Interested? Contact the WSA office, who will help you get started.

1-800-838-0879 or  
[support@wellspouse.org](mailto:support@wellspouse.org)

## LETTERS



My complimentary copy of *Mainstay* came at the best time for me. It made me realize all the feelings I'm experiencing are ok. My IS has been sick for 2 years now with lung cancer. He's now in a nursing home for four months. Friends and family think they're helping, but if I hear them tell me, "you're strong," or "take one day at a time," I'll scream. Nobody understands unless they've gone through this.

Thank you and I'm eager to receive my next quarterly issue. – *Rosemary Hudson, Revere, MA*

Another easy-to-read newsletter. Hip hoorah, a Support Group Leader Training workshop (at the national conference) all by itself at last! What a great moment. Congrats. – *Maggie Strong*

My issue of *Mainstay* arrived the other day and I noticed, with sadness, the death of Debbie Hawke's husband Ken. I will call Debbie to let her know that I, too, have lost my husband. We are part of the original 10 who started Well Spouse.

Looking back in the records, you'll see we started in 1988 after Maggie Strong and I had a meeting in Philadelphia where she appeared on a TV show. Maggie suggested the first meeting be held here in Philadelphia, so I arranged to use Pendle Hill, The Quaker Study Center. I also ran local support group meetings here in Philadelphia for three years.

To say I am proud of what Well Spouse® has become is an understatement. The respite weekends, the conferences, the well-written newsletter, the friendships that are formed and nourished because of the circumstances of our lives show the need in our society for our group. We've come a long way since our beginning.

It has almost been a year since I lost my husband, John. I guess we get used to this new phase of life in time, but it does not come easily, especially when it comes so unexpectedly.

Keep up the good work. – *Jan Beaty, Willow Grove, PA*

Thank you for all the good work you do for caretakers. It has been a gift to me in so many ways. I have recommended Well Spouse® to many other caregivers and have suggested that our Pastoral Care heads get connected so that they can share it with patients and families. – *Kathy Feddor*

I am writing this letter to express my gratitude for all the kindness and support I received at my first experience with the Well Spouse® Association. I was having so many issues in dealing with my husband's MS at home, and I went online for support, and found this organization. I emailed different contact people, and got immediate help and direction. I went to the Rock Hall respite by myself, from Ft. Lauderdale, without knowing anyone ... I immediately felt like part of the group, and had loads of fun as well. The sunset sail was very special, and the whole experience recharged my batteries ... Again, I thank you and you should all be proud of your great organization. – *Margie, Ft. Lauderdale*

I am the ill partner of one of your members. Early this year we learned that I have progressive MS, and then a few short weeks later it was confirmed that I had prostate cancer.

The point of my writing is to say thank you to my wife who has just been a rock through all that we have had to deal with. I also want to let each and every one of the caregivers out there know that they are truly APPRECIATED FOR THE SACRIFICES they make for us each and every day. We do care about how they are feeling and what is going on in their worlds - separate from ours.

One of the things that is the most bothersome to me is that very few people ever ask my wife how SHE is doing; the only one who does is her best friend. They talk each and every day. Otherwise, it is as if she is invisible. Even in the doctor's office, when the reason for the visit is that she is sick, he wants to know how I am doing before asking her what brought her to the office.

Nineteen years ago, my siblings and I had to help my mother during my father's final days. I understand the stress that is put upon a caregiver and I want to let all caregivers know how grateful we who need their care are for them. – *Michael Robinson*

## Expectations and Stress — by Kelly Brunn

People often ask, “What is the most stressful part about being a well spouse?” My initial reaction is “It depends on the day.” The truth is the smallest most insignificant thing can completely stress me out, while things that you would think would be the most certain stress factors sometimes pass without much affect.

In evaluating why that’s the case, I discovered it all boils down to *my expectations and experiences*. I get the most stressed when my expectations for the task, day, or week don’t line up with reality. Sometimes that’s because reality can be extremely overwhelming when you’re a caregiver.

**Many times the “cure” for minimizing stress is reassessing the expectations and correcting them or evaluating what my control factor is in the situation.**

Things that I have experienced numerous times as a well spouse, I have a much better handle on, and they become “routine” in my day rather than stressful. It’s the new unexpected twists that can set me off. Unfortunately, sometimes that can be an emotional reaction my husband expressed that hadn’t been present in previous situations.

I’ve learned over the years of being a caregiver that getting stressed out over things I have absolutely no control over brings me down the most. Obviously the extreme vulnerabilities of being a caregiver mixed with emotional reactions can make a situation unbearable...regardless of the cause.

Sometimes it’s being the wage earner in the family and feeling trapped by extreme financial obligations to provide the best care possible for my spouse.

Sometimes it’s having the lost dreams staring me in the face with an unclear view of what the “replacement dreams” might be.

Sometimes it’s feeling like a single parent when “technically” I’m not one.

I’ve learned over the years of being a caregiver that getting stressed out over things I have absolutely no control over brings me down the most.

Sometimes, it’s knowing on a Friday night that the most excitement I can count on is television reruns and my spouse falling asleep at 7:30, which leaves me sitting there feeling like I’m at the end of my life rather than in the middle of it.

Finding a quick mitigating strategy for the stress is important, regardless what the underlying source of the stress might be. What has worked for me?

- Physical relaxation (for me a warm bubble bath at the end of the day).
- A walk with headphones to escape the mental drain while allowing some release physically can also redirect my energy.
- A glass of wine or just a few moments alone with my journal to release the feelings can be the cure.
- Finding people to socialize with helps me feel like I’m still a whole person.

I don’t think as a well spouse we ever find a constant balance, but recognizing when the scales are tipping far too much on one side is a step in relieving the stress.

There’s no one way to endure this caregiver journey; it’s one day at a time and sometimes one hour at a time.

*Kelly Brunn’s husband, Bill, suffered from multiple sclerosis. He passed away in July 2006.*

**Memorial Gift**

To make a memorial donation, please fill out this card and mail it with your donation to:  
 Well Spouse® Association  
 63 W. Main St., Suite H  
 Freehold, NJ 07728

Name of donor: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City, State, Zip: \_\_\_\_\_  
 Email: \_\_\_\_\_  
 Gift in memory/honor of: \_\_\_\_\_  
 \_\_\_\_\_  
 \*Please notify the following this gift has been made:  
 Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City, State, Zip: \_\_\_\_\_  
 \_\_\_\_\_  
 Amount of Memorial Donation: \$ \_\_\_\_\_.

**Well Spouse® Association**

**Main Office:**

63 West Main Street, Suite H, Freehold, NJ 07728  
 (800) 838-0879 or (732) 577-8899

Fax us at 732-577-8644

Email us at [info@wellspouse.org](mailto:info@wellspouse.org)

Visit us online at [www. Wellspouse.org](http://www.Wellspouse.org)

**Membership Services:**

Contact the main office or email  
[members@wellspouse.org](mailto:members@wellspouse.org)

**MAINSTAY:**

Mail your comments, questions, and submissions to  
 WSA Mainstay  
 60 West Main Street, Suite H  
 Freehold, NJ 07728-2141  
 Or email [mainstay@wellspouse.org](mailto:mainstay@wellspouse.org)

**Support Groups:**

Contact the main office, visit our website or email  
[support@wellspouse.org](mailto:support@wellspouse.org)

*“When one is sick ... two need help”*

**WSA Membership Dues and Donations**

**Comp Issue Newsletter**

Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_  
 Phone: \_\_\_\_\_ Preferred Username for Login \_\_\_\_\_  
 Email: \_\_\_\_\_  
 Spouse’s Illness/disability: \_\_\_\_\_  
 \_\_\_\_\_ Current Caregiver      \_\_\_\_\_ Spouse Deceased  
 \_\_\_\_\_ Spouse in nursing home      \_\_\_\_\_ Separated/Divorced  
 Children: Y / N Ages: \_\_\_\_\_  
 Your age: \_\_\_\_\_ 20-35    \_\_\_\_\_ 36-45    \_\_\_\_\_ 46-55    \_\_\_\_\_ 56-65    \_\_\_\_\_ 66+

**Well Spouse Membership:**  
 \_\_\_\_\_ One Year ..... \$30  
 \_\_\_\_\_ Two Year ..... \$55  
**Supporting Memberships:**  
 \_\_\_\_\_ Friend of WSA ..... \$25  
 \_\_\_\_\_ Professional/Clergy .. \$50  
 \_\_\_\_\_ Organization/  
 Institution ..... \$100

**Additional Contributions:**  
 General Donation..... \_\_\_\_\_  
**Total Paid** ..... \_\_\_\_\_

Membership Type: \_\_\_\_\_ New      \_\_\_\_\_ Renewal      \_\_\_\_\_ Updated Information  
 \_\_\_\_\_ I would like more information on starting a support group in my area.

No well spouse is denied membership due to financial hardship. Please send what you can afford at this time, minimum of \$5.

Annual membership includes a subscription to *Mainstay*, all WSA mailings, and participation in regional support groups (where available). We also give information on workshops, respite weekends, and conferences. Your dues help cover mailing costs and underwrite the operating cost of our online website and other support programs.

;

## *SAVE the DATE...*

*WSA National Conference – Held annually in October*

☐ WORKSHOPS

☐ RESPITE

☐ SHOPPING

☐ DINING

☐ DANCING

*Meet up with old friends and make new friends. Please join us this fall!  
See website for details.*

## The Window

By Dorothy Saunders

I steel myself  
as I enter the critical care unit.  
Long ago robbed of use of his limbs,  
he now cannot speak  
as a ventilator inflicts yet another cruel indignity  
on his battered spirit,  
even as it breathes for him,  
his mechanical guardian angel  
until his strength returns.  
His dark eyes are pools of pain and frustration  
as he tries to make his needs known.  
At times I avert my eyes  
from his struggles,  
lest I get swallowed by grief and helplessness.  
That his bed is by a window  
is a serendipitous gift –  
I gaze outside  
to connect with life,  
to be reassured  
by its mundane constancy.

I glimpse women  
heavy with new life  
trudging up the hill,  
the arriving and departing staff  
so skilled and compassionate,  
folks of all ages and races  
waiting for the bus.  
I watch helicopters land  
with human cargo also needing medical miracles.  
This crisis is so protracted  
that I have witnessed the seasons change.  
Glorious fall foliage has given way  
to strings of Christmas lights  
in the hospital's evergreens.  
As winter descends  
I sit in the sunlight  
beaming through the window,  
shifting my chair  
to linger in its warm embrace.