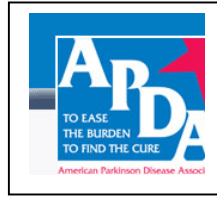


American Parkinson Disease Association, Inc
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All Support Group Meetings are for PD Patients, their Caregivers, Family and Supportive Friends.

Alamo Area PD Support Group

Second Monday every month except Oct, 1 PM. Sunset Ridge Church of Christ, 95 Brees Blvd, San Antonio (SA)

Young-Onset PD Support Group

Second Saturday every month, 10 AM

Newforest Estates, a Senior Lifestyle Community, Auditorium, 5034 New Forest Dr SA

DBS Support Group "Live Wires"

Fourth Saturday every month, 10 AM - Location varies; call Sandra Farris, 830-257-3811

sandraf@windstream.net or Judy Hoopman 830-997-

7705 ralanh@beecreek.net for current location

Caregivers Only Support Group,

Second Tuesday every month, 10 AM, Bob Ross Senior Ctr, 2219 Babcock Rd, SA, TX - POC: Dianne Johnson, 210-567-6688, 651-9835, diannejohnsonrn@aol.com .

Burnet PD Support Group

Second Tuesday every month, 1 PM. Burnet PC Tng Ctr, Highlander Inn, 401 W Buchanan Dr (Hwy 29), Burnet POC Mark Vidas, 512-756-4949, info@burnetPC.com

Lower Rio Grande Valley PD Support Group

Needs someone to take responsibility of Support Group Leader - Contact Pauline Frink 956-421-3360, pgfrink@sbcglobal.net for more info.

Argent Court Assisted Living Support Group

Fourth Thursday every month, 2 PM. 508 Old Austin Hwy, Bastrop. POC: Shasta Martini 321-9500 #252, Jenny Bankston 252-1512

Georgetown PD Support Group

Last Thursday every month, 2PM. Scott & White Meeting Rm, 4945 Williams Dr Georgetown, POC: Beverly Edwards 512-863-8443

edwards107@verizon.net

Parsons House PD Support Group

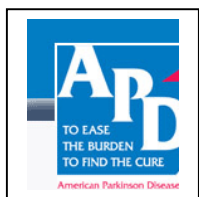
Third Friday every month, 10 AM. 1130 Camino La Costa, Austin, POC: Jaime Eyer 512-454-0524

Ranch Retirement Living Support Group

Last Friday every month, 1 PM. 1301 Whitestone Bl, Cedar Park. POC 996-0700 Ms Bryson 238-6000

Comal County Support Group

Fourth Saturday every month, 10 AM. 801 W San Antonio St, New Braunfels (McKenna Event Ctr Children's Museum). POC: Tommy Dubuque tommydubuque@yahoo.com or call 830-606-2160



American Parkinson's Disease Association, Inc
 Alamo Area Parkinson Support Groups
 5368 Fredericksburg Rd, Suite 200, San Antonio, Texas 78229-6108
 Phone 210-349-0096, www.aapsg.org
 APDA I & R Center Phone 210-567-6688

Quarterly Newsletter, January 2008

Editor: Dianne Johnson

Local News

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You may leave a message for any AAPSG Officer or Board Member at 210-567-6688.

HAPPY NEW YEAR

We wish you a wonderful and joyous New Year, and pray that we achieve a cure this year. Until we do **NEVER GIVE IN**.

Thank you for your support

Local Research Studies Funded by APDA. Congratulations to **James L. Roberts, PhD**, UTHSCSA, who received the prestigious Roger Duvoisin Grant for his study of Molecular and Cellular Mechanisms of Estrogen Mediated Neuroprotection of Mesencephalic dopaminergic Neurons. To **Syed Iman, PhD**, UTHSCSA who received a grant to study Evaluation of stress-induced Tyrosine Kinase, c-Abl, as a Novel therapeutic target for PD, and to **Andrea Giuffrida, PhD**, UTHSCSA who received a grant to study the Neuroprotective role of Cannabinoids in PD. All have received generous grants from APDA Research Funding for fiscal year 2007-2008.

The Lower Rio Grande Valley Support Group needs someone to take over responsibility of Group Leader. After many years of devoted work as Group Leaders, Pauline & Bill Frink have to pass the torch of leadership. So if you live in the Harlingen area and can step forward please contact Pauline or Bill at 956-421-3360, pqfrink@sbcglobal.net for more info. Now is the time to get involved.

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Velcro Closing Shoes

For those of you who have been wondering if Velcro straps on shoes work as well as regular shoe strings, you can stop wondering. I have worn a pair of shoes with Velcro straps for a year and in my opinion they work just as well if not better than shoe laces. I didn't test an expensive name brand either.

Doak Walker

Questions & Answers

Q. What is the difference between Lewy Body Dementia and other dementias, such as Alzheimer's Disease?

A. Lewy Body Dementia (LBD) is characterized by dementia plus two or more of the following features: Parkinsonism; recurrent fully formed visual hallucinations; fluctuations in cognition and/or arousal; and REM sleep behavior disorder (RBD).

The parkinsonian features include less facial animation, stooped posture, shuffling gait, and slowness of movement. Tremor, an unintentional to-and-fro movement, may also be present. The hallucinations can involve vivid visions of people or animals, often with the same imagery and perceptions from day to day. Cognitive problems are usually notable in judgment, problem solving, complex decision-making, and multitasking, as well as in visuospatial functions (required for activities such as driving). Memory may or may not be impaired.

Sleep disorders may cause problems with cognition and arousal as well as excessive daytime sleepiness. RBD refers to the tendency for people to 'act out their dreams.' During normal REM sleep, our brains are active but most of the muscles in our bodies are still. But in RBD, the muscles are abnormally active, and injuries such as bruising, pulled hair, and even fractured bones can occur. The dreams often have a nightmare quality with the person being chased or attacked.

These features contrast with other common dementia syndromes. In Alzheimer's Disease, forgetting the details of recent events and upcoming appointments is the prominent early feature. Parkinsonism and hallucinations occur late in the disease if at all, and RBD is extremely

rare. Frontotemporal dementia is manifested by marked changes in personality and behavior and/or language, whereas memory and visuospatial functioning tend to be minimally affected. Parkinsonism and visual hallucinations are uncommon in frontotemporal dementia, and RBD is also rare.

Answer by Bradley F Boeve, MD, Associate Professor of Neurology at the Mayo Clinic in Rochester, MN.

Neurology Now, November/December 2007

Lewy Body Dementia Association, Inc

Lewy Body Dementias are the second leading cause of degenerative dementias in the US – affecting over 1.5 million individuals and their families. The LBDA is a national 501(c)(3) organization that supports those affected by Lewy Body Dementias and promotes research for a cure. Families can call our Caregivers' Helpline which offers an opportunity to ask questions, seek information, and connect with other experienced LBD caregivers. This is available through our Toll-Free Helpline (1-800-LEWY-SOS or 1-800-539-9767) and also through our E-mail Helpline support@lbda.org. You can also visit our online forum which can be accessed through our website, <http://www.lewybodydementia.org/forum/>. This forum focuses on LBD issues and may provide you with additional information and connections with individuals, families, and caregivers living with LBD. In addition, we link caregivers and families to local and online support groups. Please visit this link to learn more about these groups:

<http://www.lewybodydementia.org/sptgroups.php>

I hope that you will not hesitate to contact me or the LBDA team at any time if you have questions or concerns. Catherine Doyle, Development & Program Coordinator.

Lewy Body Dementia Association, Inc.

P.O. Box 451429

Atlanta, GA 31145

(phone) 404-935-6444 (fax) 480-422-5434

lbda@lbda.org / www.lewybodydementia.org

PRAY FOR A CURE

The following article has nothing to do with PD directly, but all of us are affected by it either personally or by our caregiver.

Women and Heart Attacks (Myocardial Infarction)

I was aware that female heart attacks are different, but this is the best description I've ever read. Did you know that women rarely have the same dramatic symptoms that men have when experiencing a heart attack...you know, the sudden stabbing pain in the chest, the cold sweat, grabbing the chest & dropping to the floor that we see in the movies. Here is the story of one woman's experience with a heart attack.

"I had a completely unexpected heart attack at about 10:30 pm with NO prior exertion; NO prior emotional trauma that one would suspect might've brought it on. I was sitting all snugly & warm on a cold evening, with my purring cat in my lap, reading an interesting story my friend had sent me, and actually thinking, A-A-H, this is the life, all cozy and warm in my soft, cushy Lazy Boy with my feet propped up." A moment later, I felt that awful sensation of indigestion, when you've been in a hurry and grabbed a bite of sandwich and washed it down with a dash of water, and that hurried bite seems to feel like you've swallowed a golf ball going down the esophagus in slow motion and it is most uncomfortable. You realize you shouldn't have gulped it down so fast and needed to chew it more thoroughly and this time drink a glass of water to hasten its progress down to the stomach. This was my initial sensation---the only trouble was that I hadn't taken a bite of anything since 5:00 p.m.

"After that had seemed to subside, the next sensation was like little squeezing motions that seemed to be racing up my spine (hind-sight, it was probably my aorta spasming), gaining speed as they continued racing up and under my sternum (breast bone, where one presses rhythmically when administering CPR). This fascinating process continued on into my throat and branched out into both jaws.

A HA!! NOW I stopped puzzling about what was happening--we all have read and/or heard about pain in the jaws being one of the signals of an MI happening, haven't we? I said aloud to myself and the cat, "Dear God, I think I'm having a heart attack!" I lowered the foot rest, dumping the cat from my lap, started to take a step and fell on the floor instead. I thought to myself, if this is a heart attack, I shouldn't be walking into the next room where the phone is or anywhere else.....but, on the other hand, if I don't nobody will know that I need help, and if I wait any longer I may not be able to get up in moment.

I pulled myself up with the arms of the chair, walked slowly into the next room and dialed the Paramedics... I told her I thought I was having a heart attack due to the pressure building under the sternum and radiating into my jaws. I didn't feel hysterical or afraid, just stating the facts. She said she was sending the Paramedics over immediately, asked if the front door was near to me, and if so, to unbolt the door and then lie down on the floor where they could see me when they came in.

"I then lay down on the floor as instructed and lost consciousness. I don't remember the medics coming in, their examination, lifting me onto a gurney, getting me into their ambulance, or hearing the call they made to St. Jude ER on the way. But I did briefly awaken when we arrived and saw that the Cardiologist was already there in his surgical blues and cap, helping the medics pull my stretcher out of the ambulance. He was bending over me asking questions (probably something like "Have you taken any medications?") but I couldn't make my mind interpret what he was saying, or form an answer. I nodded off again, not waking up until the cardiologist and his partner had already threaded the teeny angiogram balloon up my femoral artery into the aorta and into my heart where they installed 2 side by side stents to hold open my right coronary artery.

I know it sounds like all my thinking and actions at home must have taken at least 20-30

minutes before calling the paramedics. But it actually took 4-5 minutes before the call. Both the fire station and St. Jude are only minutes away from my home. My cardiologist was ready to go to the OR to start my heart which had stopped somewhere between my arrival and the procedure.

Why have I written all of this to you with so much detail? Because I want all of you who are so important in my life to know what I learned first hand.

1. **Be aware** that something very different is happening in your body. Not the usual men's symptoms, but inexplicable things happening (until my sternum and jaws got into the act). It is said that many more women than men die of their first (and last) MI because they didn't know they were having a MI. They commonly mistake it as indigestion, take some Maalox or other anti-heartburn preparation, and go to bed, hoping they'll feel better in the morning when they wake up...which doesn't happen. My female friends, your symptoms might not be exactly like mine, so I advise you to call the paramedics if ANYTHING unpleasant is happening that you've not felt before. It is better to have a false alarm ER visit than to risk your life guessing what it might be.

2. Note that I said "**Call the paramedics**". LADIES, TIME IS OF THE ESSENCE! DO NOT try to drive yourself to the ER--you're a hazard to others on the road, and so is your panicked husband who will be speeding and looking anxiously at what's happening to you instead of the road. Do NOT call your doctor. His assistants (or answering service) will tell you to call the paramedics. The paramedics carry the necessary equipment, principally oxygen that you need ASAP.

3. **Don't assume** it couldn't be an MI because you have a normal cholesterol count. Research has discovered that a cholesterol elevated reading is rarely the cause of an MI (unless it's unbelievably high, and/or accompanied by high blood pressure). MI's are usually caused by long-term stress and inflammation in the body,

which dumps all sorts of deadly hormones into your system to sludge things up in there. Pain in the jaw can wake you from a sound sleep. Let's be careful and be aware. The more we know the better chance we could survive.

A cardiologist says if everyone who gets this sends it to 10 people, you can be sure that we'll save at least one life.

Limiting Stress

By Fay Rhodes

No one needs to tell a person with PD that the stresses of life have a physical effect. When we are stressed, we shake harder, move slower, spend more time "off" and experience more of the pain of dystonia. If we're going to optimize our physical condition, we need a strategic defense.

What many people don't realize is that happy events can create nearly as much distress as unhappy events.

When I was newly married, I was working full-time, leading the APDA Massachusetts Chapter and maintaining a home. Since I also had a couple of grown sons living at home, the new step-parent factor came into play rather quickly. To top it all off, my new husband was the minister at a church 50 miles away, which meant he faced a grueling commute every day and I added another job as a pastor's wife. Marrying my husband was a very happy thing. But despite my marital happiness, the stress I faced was scaled up dramatically.

I've also faced the other kind of stress. During one six-month period my husband of 20 years left me, I became a single mother of three sons, my father was diagnosed with cancer, my mother was diagnosed with congestive heart failure, my son's best friend committed suicide and my car was totaled. I can testify that stress is stress. Good or bad, it's all the same in its effect.

A little bit of stress is a good thing. It prepares us for emergencies, sharpens us for competition and motivates us to solve our problems.

Unrelenting stress is another story.

While each of us needs to develop individualized strategies, there are some things all of us can do to protect our bodies, our relationships and our

job performance from the consequences of stress.

Identify the Stressors in Your Life

While some of us are adrenaline junkies, others of us want nothing more than to spend weekends and quiet evenings at home. Some of us are natural leaders; others are only comfortable in supporting roles. Some of us run to our families for comfort, others of us run from our families for comfort. In other words, we're all different and we need to understand what it is that increases stress in our lives. Remember, a general cannot plan an effective battle strategy unless he knows his enemy.

Pay attention to what happens when a stressful event occurs. Are you sleep-deficient, embarrassed, frustrated, taking on too much responsibility, compromising your values, over-scheduled or overloaded? Are you involved with toxic people — people who cause you more harm than good?

Eliminate the No-Brainers

When you come up with your list, you may realize some things can simply be eliminated. If horror movies, action movies or "tear-jerkers" leave you sleepless, stop going to movies. If coffee leaves you jittery, switch to decaf or stop drinking coffee altogether. If city driving sends you over the edge, find someone to drive you, or take the bus. You get the idea.

Re-examine the Commitments You've Made

Will the organization you lead really fall apart if you resign? Are you always the room mother at school? Most of us like to think we're indispensable, but that's almost never true. Are you in a destructive relationship? Are your professional obligations kept at the expense of your health and your family's happiness? Are you living up to your own standards or someone else's? Are your standards realistic?

HELP EACH OTHER

Get Help with Your Assessment and Goal Setting

This is where a professional counselor can be of great help. If you can't afford that option, find a friend and ask for honest observations. (Be sure you don't resent their observations.) Keep in mind; you don't have to tackle every challenge at once. Break down the work into small tasks. Achieving many small victories will encourage you over the long haul.

Many people find prayer or meditation effective as tools for dealing with stress. If these are a part of your life now is the time to put them into practice for your well being. There are a variety of counselors, teachers and clergy trained to assist you.

Schedule Downtime and Keep it Sacred

Be proactive about giving priority to restoration time. For my boss, an extrovert, that means he needs to spend time with lots of people and activity. For me, an introvert, that means spending time alone, with my husband or my knitting needles. Decide what de-stresses you and make it a priority - no matter what anyone else thinks! Develop new interests. Don't wait for your mid-life crisis, if you don't know how to relax, learn.

Get Exercise and Eat Healthy

Make changes gradually here. Walking a mile or two may be better and more sustainable for you than running or working out at a fitness club. Cutting out caffeine and eating more fruit and vegetables may make a marked difference in how you feel. Personally, I would not feel good if I eliminated ice cream from my diet, but I don't miss donuts and caffeine at all. People who set tolerable goals for diet and exercise are more likely to make progress than those who start right off with unpalatable or overly ambitious goals.

Don't Worry About Things You Can't Control

This takes practice, but it's key to reducing stress in your life. Worrying doesn't fix anything. Prepare for stressful events (that job interview, church solo, professional presentation), then do your best. You simply can't do more than that.

Try to Resolve Conflicts with Other People

If you aren't successful, you may need to limit or eliminate a troublesome relationship, look for other work, stay home for the holidays or get caller ID.

Get as Much Sleep as Possible

For people with PD, this can be a real challenge. Currently, I'm lucky if I get six hours of sleep at night. In order to get enough sleep I usually need a nap after work. Luckily, my husband and I are stay-at-home people, so it has not required a change of lifestyle. If your evenings are activity-filled, you may need to re-fuel and add a restorative nap to your schedule.

Try to Look at Change as a Positive Challenge

Consider change in your life an opportunity to grow and develop as a person. If you're competitive, take on the challenge of creating and reaching new goals. If you have never had to face radical changes before, this is your opportunity to discover new truths.

The fact is you can't control your circumstances or other people. The only thing you are solely in charge of is your attitude. It is fundamental to everything you do or attempt to do. It's the difference between being content and being miserable. If you refuse to take responsibility for your own attitude, you and everyone around you will suffer.

Seize the day and appreciate the heck out of it! •

Faye Rhodes is a past president of the APDA Massachusetts chapter. This article was originally published in the spring 2007 issue of APDA Young Parkinson's newsletter.

Avoiding Caregiver Burnout

By Pat Olsen

Ever since Chris Donham first started showing signs of Alzheimer's disease, her husband Mark has taken her on motorcycle trips around the country to visit friends and family. A year and a half ago, he left his job as a sales representative to become a full-time caregiver for Chris. The couple, from Lake Oswego, OR, may seem young to be in this situation—Mark is 45, and

Chris, who has early-onset Alzheimer's, is just 51—but they are not alone. Caregiving is an equal opportunity employment; it is also a labor of love. And if you aren't careful, it can burn you out.

Sources of Burnout

Mark's devotion to Chris is obvious: A few months ago, he hung family photo collages throughout the house to keep memories alive for her. Not only does he make sure they go on walks every day he's also taken her cross-country to visit friends. Mark's strong religious beliefs and a local Alzheimer's support group have helped him cope with a difficult situation.

He knows he has to take care of himself too. "You don't realize how much stress and strain there is" Mark says. If you look at the statistics for caregivers of Alzheimer's patients, 50 or 60 percent have health problems. In a study reported in the September 2007 issue of the Journal of Immunology, researchers found that caring for an Alzheimer's patient can shorten a person's life by four to eight years. Over 40 percent of these caregivers report high levels of emotional stress, according to the Alzheimer's Association.

"There are two potential sources of caregiver burnout", says Lisa Shulman, MD, Associate Professor of Neurology at the University of Maryland, who conducts studies on caregiving in Parkinson's disease. "There's both emotional strain and physical strain," she notes. Although we usually think first of the emotional strain of caregiving, providing for the needs of a person with disabilities also takes a physical toll.

"Physical symptoms can include exhaustion, difficulty sleeping, changes in appetite or weight, and a tendency to get sick more often than in the past," says Robert Heinssen, PhD, Clinical Psychologist and Researcher at the National Institute of Mental Health.

The importance of self-care was brought home to Mark recently. After dropping his wife off at her once-a-week respite care at a local community center, he ended up in an emergency

room with signs of a possible heart attack. He was fine, but it was the wakeup call he needed.

He is increasing Chris' respite care to twice a week and plans to get in-home care once a week. He is also wise to have sought out a support group. According to a recent study in the Journal of Neurology researchers found that when Alzheimer's caregivers get support and counseling; it benefits them and can keep the patients they care for out of a nursing home longer.

When it comes to making big decisions about care, don't wait until a crisis hits.

Caregiving 101

"It's so easy to get burned out caring for someone," warns Janet Jankowiak, MD, a Geriatric and Behavioral Neurologist at Radius Specialty Hospital in Boston. Her father has Alzheimer's and is in an assisted living facility Dr Jankowiak finds that keeping her dad organized and on a schedule and providing as much structure as possible—from writing his activities on a calendar to arranging his clothes for the week—helps them both immensely. One holiday she thought that having him visit with the family the entire day would be enjoyable, but he "sundowned," becoming anxious as evening began. Dr Jankowiak realized they both would have been better off had she just invited her father for dinner like always, she says, which is in keeping with a suggestion from the Alzheimer's Association to try and maintain the person's normal routine during holidays.

Dr Jankowiak sets an example for others in situations like hers by exercising and getting assistance. "If you're the primary caretaker and something happens to you, there's no one else to do it," she says. She has also enlisted her teenage son in the caregiving process, and he has been an enormous help with her father. Dr Jankowiak also hires additional aides to help her dad at the facility.

"Depending on the disease", says Dr Shulman, "your loved one has two competing needs: one for assistance and the other for independence". If a caregiver provides too much assistance, it can result in an adverse consequence—the patient may do less than he is able. This can lead to the patient "giving up" and allowing himself to be treated like a child. But it's also a priority to be fully attentive to the patient's needs. "Caregivers walk a tightrope", Dr Shulman explains.

Don't Wait to Make Decisions

Mark has learned another important lesson about caregiving: When it comes to making the big decisions, don't wait until a crisis hits. He borrowed the mantra "Sooner rather than later" from a woman in his support group and is starting the search for long-term care now. Years ago he and Chris prepared for the possibility that she'd fall ill; her family carries the gene for early-onset Alzheimer's and several of her family members died of the disease before age 55. First came investment planning so that Mark could care for Chris at home when the time came. Then the couple took care of wills and other legal documents and bought long-term care insurance for her. Investigating nursing homes now helps ease his mind.

Stephen Sergay MD, president of the American Academy of Neurology, seconds Mark's advice about decision-making. Although he was living in the US, thousands of miles away from his parents in South Africa, Dr Sergay experienced many caregiver challenges. When their health declined to the point where they needed assisted living, he traveled to their home to tour assisted living facilities with them. Invariably his father would put down a deposit and call Dr Sergay as he was boarding a plane back to the States to say he had changed his mind. It took visits to 10 facilities before his father accepted the change he was about to make.

Emotional Caregiving

1. Be Honest With The Person Receiving Care: Acknowledge that it's not an easy decision, but that you need it for your own well-

being. Be sensitive to the person's feelings about being a burden, spending money, and having a stranger help with care. You might say "I wish I could continue doing _____, but I just can't. You're very important to me and it would be a great relief if I knew your needs and my needs were being met."

2. Lean on Friends: Friends who listen and offer advice only when asked are invaluable. Ask outright if you can use your friend as a sounding board when you need to. If just one person can do this, try not to overburden him or her.

3. Try A Support Group: Support groups are good ways to blow off steam and share ideas with people facing similar situations. An online support group is good for homebound caregivers. Hot lines can help when a crisis strikes.

4. Consider Therapy: If you frequently feel depressed, overwrought, or overwhelmed, get help from a psychiatrist or therapist. If you don't know where to turn, ask your doctor for a referral.

Source: Caregiver's Handbook: A guide to caring for the ill, elderly, disabled...and yourself (Harvard Health Publications, updated 2007)

Attitude is Everything

Understand that caretaking is a process that may involve everything from changing where your loved one resides to revising what you accept as normal. The timeline requires that you be gentle and have patience. If you understand this, Dr Sergay says, you'll be calmer and better equipped to deal with your role. For example, you might choose respite daycare within a larger, long-term facility to introduce your loved one to the idea of long-term care. If you know your family member is comfortable with a facility then you'll feel more comfortable, too.

To reduce your anxiety, don't hesitate to include your family doctor and neurologist in conversations about long-term care for your family member, advises Dr Sergay. His patients and their families often make an appointment

with him to chat about a family member's future. It's not unusual for them to have several additional appointments. Finally try to be tolerant, Dr Jankowiak suggests. Realize that your loved one isn't deliberately trying to annoy you when he does things that seem to make no sense. If you've told him something 10 times, take a deep breath and have faith that he's trying to do his best.

Handling Guilt

Probably all caregivers feel guilty at one time or another. Maybe you feel you're not providing enough care, or the right kind of care, for your loved one; or maybe you're upset that you've lost patience occasionally. You may feel bad about wanting more time for yourself, or you may be having a hard time with all that's involved in caregiving. This is natural, but it also may be a sign that you need a break.

You can't be a good caretaker if you don't take care of yourself. A commonly-used analogy is the advice given to airline passengers on takeoff: In an emergency fasten your own oxygen mask first before attending to a child's mask. The same principle applies to caregiving. You've got to tend to your needs first if you're to be responsible for another person.

If you're involved in long-distance caregiving, you're likely dealing with the guilt of not being physically present. You may not feel as physically drained as a caretaker who's present all the time, but that doesn't mean you're not worried and anxious. The National Institute on Aging suggests that you remember you're doing the best you can in your situation, and to take comfort in knowing that you're not alone. Support groups can also help long-distance caregivers.

Beyond Long Term Care: What about You?

Emmy Valpicelli, 59, of Tinton Falls, NJ, is testimony to the depression that can hit caretakers after a loved one enters a nursing home. When her husband Tony 61, had a stroke a few years ago, she left her job as a medical biller to care for him full-time. The petite brunette tried hiring aides but felt that no one could care

for her strapping husband quite like she did, even with their size difference.

Like Emmy half of all caregivers care for a loved one alone, according to the Caregiver's Handbook: A Guide to Caring for the ill, elderly, disabled... and yourself (Harvard Health Publications. updated 2007). If her husband's stroke was the first blow to Emmy's serenity having to move him to a nursing home when he developed additional medical problems was the second. Not only was she wracked with guilt, she felt empty.

"Since I was no longer caring for him, I had no identity and I didn't know what to do next," she says. Worried at seeing their mother sitting around moping, her two grown daughters pressed her to find something that excited her. Years earlier Emmy loved to go out dancing, so she decided to take ballroom dancing lessons as a refresher. Now she advises all caregivers to find something they love to do.

"It changed my life," says Emmy beaming. "I have confidence now," she adds, explaining that dancing teaches you to hold yourself erect and present a self-assured image that affects your whole outlook. She's 15 pounds lighter, she feels great, and she has acquired a whole new group of friends. She even enters dance competitions. Asked if she had one thing to do over in caring for her husband, what would it be? Emmy's answer is instructive for other caregivers. "I think I would take all the help I could get", she says, "Whether you do something better than someone else or not, it still gets done."

Finding the Joy

As a devout Christian, Mark feels it's an honor and privilege to care for his wife, regardless of the stresses that come with the job. He has one last thought for caregivers. "For all the negative things about being a caregiver, there are some times that are just amazing", he muses. "We tend to forget the joy of the moment, where things are vivid and real."

He describes watching a sunset over the water with his wife one day. Chris was exuberant on catching sight of the brilliant red and orange sky and then she glanced away. When she turned back, it was as if she were seeing it for the first

time. "There is joyfulness in those moments", Mark says, "joy that comes with letting go of expectations and cherishing the relationship that is still very much alive".

Practical Caregiving:

- 1. Get Organized:** File paperwork under key topics: medical care, benefits, resources, assisted living, etc.
- 2. Keep the Person's Medical History and Medication List Handy:** Store these in a binder in which you log conversations—to whom you spoke, when, and what was suggested.
- 3. Coordinate Medical Care:** Each doctor should know what the others suggest and what medications the patient is taking.
- 4. Ask Until You Have Answers:** Don't be afraid to ask for simpler explanations, a breakdown of the risks and benefits of a particular treatment, or a second opinion.
- 5. Be Informed:** The National Institutes of Health's Medline plus Web site www.medlineplus.gov offers reliable information on hundreds of conditions.
- 6. Be Present:** At the hospital, it helps to have an extra set of eyes and hands. Tell staff if you notice confused or erratic behavior.
- 7. Network:** Get recommendations on nursing homes or home health care from social workers, doctors, nurses, friends, family members, and co-workers.

Source: Caregiver's Handbook: A guide to caring for the ill, elderly disabled...and yourself (Harvard Health Publications, 2007. Pat Olsen www.patolsen.com has written for publications such as Remedy, Diabetic Living, and Bipolar magazine. Like many people, she has caregiving experience herself.

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