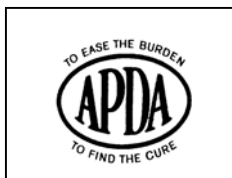


American Parkinson Disease Association, Inc
5368 Fredericksburg Rd, Suite 200
San Antonio, TX 78229-6108



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AAPSG Calendar, January 2004 – March 2004

All Support Group Meetings are for PD Patients,
their Caregivers, Family and Supportive Friends

-- **Alamo Area Parkinson's Support Group**

Second Monday every month, 1 PM

Sunset Ridge Church of Christ, 95 Brees Boulevard

12 Jan - Griswold Special Care, General
Discussions.

9 Feb - Senior 2000 Day Care, General
Discussions

8 Mar - General Discussions

-- **Young-Onset Parkinson's Support Group**

Second Saturday every month, 10 AM

Thornton Elementary School, 6450 Pembroke

10 Jan – Dr Pappert and General Discussions

14 Feb – General Discussions

13 Mar – General Discussions

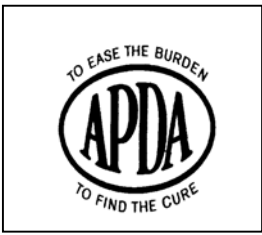
DBS Support Group “Live Wires”

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

sandyfar@omniglobal.net or Judy Hoopman 830-
997-7705 ralanh@ktc.com for current location.

**PLEASE NOTIFY US IF YOUR LOCAL
ADDRESS OR E-MAIL ADDRESS CHANGE**

Last date for submitting items for the next
newsletter is 2 Mar 2004. Send material to Doak
Walker, 7650 Hwy 90W #40, San Antonio, TX
78227-4059 or e-mail to shalom5@earthlink.net.



American Parkinson's Disease Association, Inc

Alamo Area Parkinson Support Groups

5368 Fredericksburg Rd, Suite 200, San Antonio, Texas 78229-6108
Phone 210-344-8828, www.aapsq.org

Quarterly Newsletter, January 2004

Editor: Dianne Johnson

Publishers: Carla & Doak Walker

Local News

Executive Board, 2002-2004

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You may leave a message for any AAPSG Officer or Board Member at 210-344-8828.

Thank You

Our special thanks to Cliff Hall and Senior 2000 for the donation of the food for our Christmas parties. The food was outstanding and everyone, including Santa, had more than enough to eat. If you weren't there you missed a great meal.

Medicare Update

We reported in our last newsletter that Medicare had begun to limit coverage for outpatient physical therapy, speech-language pathology and occupational therapy services. We are pleased to tell you that Medicare has announced they are delaying implementation of their announced limited coverage for two years. So check with the Parkinson's Outreach Program (POPs) at 349-0096 to start or continue your treatments. It is a great program aimed at PWP and many of our members have received excellent care. Call them and they will tell you all about the program and how to get started. Believe me you will be glad you did.

Our Web Site www.aapsq.org



developing creativity

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Study Links Extra Genes to Parkinson's

WASHINGTON - Mutated genes are not the only cause of Parkinson's disease, a study shows. Some patients have extra copies of a normal gene that cause too much of a protein to build up in their brains. The discovery, led by scientists at the National Institutes of Health (NIH), provides another clue toward potential treatments for PD. At issue is a brain protein called alpha-synuclein. Its normal function is not clear. But scientists have found alpha-synuclein mixed with other substances in lesions that clog the brains of some PD patients. A number of gene mutations have been linked to PD, including a mutated alpha-synuclein gene found in some families prone to the rare inherited form of the disease. NIH scientists had long tracked one such family from Iowa, but were puzzled. Some of the Parkinson's patients did not have the alpha-synuclein mutation like their relatives did. So scientists did a more in-depth genetic hunt, and found some relatives had four copies of the gene that makes alpha-synuclein instead of the usual two copies. Meaning they had perfectly normal protein, just too much of it in their brains.

It's a small but interesting step forward, said one PD expert, Dr. Jeffrey Vance of Duke University. It supports growing evidence in a number of neurologic disorders that how nerve cells process certain proteins is important in development of the disease, he said.

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Talampanel and Dyskinesias

Talampanel blocks a chemical called glutamate. On a theoretical basis this may be useful in slowing the progression of PD as well as in slowing the progression of dementia. However, we only have evidence now that it works for dyskinesias. At present we are studying whether it slows PD progression. To qualify for the study you must:

- Have had PD for at least 5 years.
- Have dyskinesias that are sufficiently disabling that you have considered DBS surgery.

If you are interested in more information about the study, contact Dr Lieberman at al@parkinson.org
NPF, AsktheDr

Useful Stuff

I have been told you can find a lot of useful marvelous stuff you can use, but never knew they existed, in this catalog. Call Functional Solutions, 1-8000235-7054 or go to their website www.BeAbleToDo.com and request their functional or handicapped catalog.

Another Newsletter

NPF is pleased to share with you a new program developed by Medtronic - The New Hope for Parkinson's Program. This magazine style electronic newsletter (they will mail you information if you call them) brings you the latest information on living well with PD. The goal is to serve as an informative, holistic and at times inspiring source of PD info for people with PD and their caregivers. Each month will explore topics that affect your health & well-being. The articles will keep you up-to-date on the latest advances in understanding and treating PD. You'll learn about harnessing the power of food from NPF expert dietician Kathryn Holden and explore strategies for coping emotionally and physically from authors such as Shelly Peterman Schwartz and the National Family Caregivers Alliance. New Hope for Parkinson's also delves into important topics such as working, traveling and exercising with PD. Lastly, each issue celebrates the people and organizations that make a difference in the Parkinson's community. To register for this monthly newsletter go to <http://www.newhopeforparkinsons.com> or call 1-800-675-5752.

The New Hope for Parkinson's Program does not provide medical advice. The contents of the New Hope for Parkinson's Web site and newsletter are for your general info only. Info you read here cannot replace the relationship you have with your doctor. Medtronic does not practice medicine or provide medical services or advice. You should always talk to your doctor with any questions or concerns you have about your general health, diagnosis or treatment. Health info changes quickly. Therefore, it is always best to confirm information with your health care professional.

DBS Questions

If you've been a regular reader of the New Hope for Parkinson's newsletter, you may have read about deep brain stimulation (DBS), also known as Activa® Therapy, which uses a pacemaker-like device to treat some of the symptoms of PD. Here's an opportunity to learn more. Introducing *Ask an Activa Expert*.

Through *Ask an Activa Expert*, you can have a one-on-one phone conversation with an Activa-expert to get answers to your DBS-related questions, including, How does Activa work and What are the benefits, risks and side effects? How does Ask an Activa Expert work? Simply call us at 1-800-675-5752 to set up a phone appointment. One of the Activa Experts will call you during the time that you specify. Then, ask your questions. This is your time. The Activa expert is there to listen and answer your questions. Most calls last around 20 minutes. There is never a charge to use the Ask an Activa Expert service. To set up your appointment, call 1-800-675-5752.

Being Your Own Best Parkinson's Advocate

It used to be that doctors were in charge of your health care. You sought their advice and took it, often with no questions asked. Today we know that when you are engaged and informed about your own care, you are healthier. For PD patients, finding the right treatment plan that offers the greatest relief from symptoms with the fewest side effects can be an ongoing challenge. Treating your PD is not just the doctor's job. There's a lot you can do to stay as healthy as possible for as long as possible.

To do that, you need to ask yourself candid questions about your care and your health. You also need to be willing to make changes if you find you're not satisfied.

Questions to ask when assessing your care:

- Am I getting the best possible care with my current physician? Is my doctor a movement disorder specialist or one who specializes in PD?
- Is information about my condition being shared among the different doctors I am seeing?
- Are my loved ones getting the support and information they need to help me manage my disease?

- Am I communicating with my doctor on important issues such as quality of life, medication side effects, frustrating personal and professional changes?
- Am I providing my doctor with detailed notes regarding my "on" and "off" times?
- How am I feeling? Are the drug treatments working? Do I have more "on" time than "off" time? -Am I experiencing intolerable side effects?
- Have I asked my doctor about new medications?
- Are there other treatments I should explore (e.g. physical therapy, yoga, tai chi, Activa® Therapy)?
- Am I feeling depressed?
- How is my diet? Am I getting enough fruits and vegetables? Am I drinking enough water?
- Am I exercising regularly?

Assessing your care is an ongoing process. You can begin by following these steps.

- Learn all you can about PD, how it progresses, your prognosis, treatment options and side effects. The more you know the more active you can be in your own care.
- Use the Internet as a source of info on the latest drug trials, surgical procedures and recent research. (BEWARE: A Web search on PD yields 27,000 results, most with no guarantees of quality, credibility or accuracy. Don't do or buy anything without checking with your doctor.)
- Evaluate your physician. Ask yourself: Am I getting the best possible care under the direction of this physician? While many general neurologists are capable of managing PD, physicians with extensive experience in PD and/or movement disorder specialists spend the majority of their time dealing with the nuances and subtleties of the disease. "PD is very complex," explains Jerrold Vitek, M.D., Ph.D., a neurologist and neurophysiologist at Emory Univ. "Understanding the disease and the problems associated with it are what experts bring to treatment. Medical therapy can be relatively complicated. It involves adding a drug, decreasing another, knowing how much to add, when to add it and how far to space the medications apart. Experienced specialists are experts at manipulating medications to benefit PD patients."

-Communicate with your physician. Effective treatment requires open and consistent communication between the patient, caregivers and the doctor. Share with your doctor quality of life issues, side effects and frustrating changes. Don't be afraid to ask about your treatment plan and new and experimental therapies.

- Having PD means you may be seeing a number of health care professionals. Maximize the benefit of working with this team by making sure info about your condition is shared among them.

-Encourage caregivers to attend your doctor appointments. "Often, it is my husband who catches changes in my Parkinson's and is better able to assess the state of my condition. He gives a different viewpoint than mine to the doctor," says Jill H., 47, who was diagnosed in 2002.

-Keep a journal. A journal is an excellent way to help your doctor arrive at the sometimes elusive balance of medications to minimize your symptoms. "Knowing when symptoms are worse or better relative to the dosing schedule is crucial to finding the right combination," explains Dr. Vitek. He recommends creating a grid that lists the days of the week from top to bottom and each hour of the day from left to right. Mark "off" periods in red, "on" periods in black and time with dyskinesias in a different color. It's an ideal way for a doctor to get a visual sense of your "off" periods and your day in general so medications can be adjusted accordingly.

-Evaluate your treatment plan. While there is no cure for PD, you can fight its symptoms with treatments ranging from traditional medications to new brain stimulation techniques. Unfortunately, all drugs used to treat Parkinson's may have some side effects. Advanced PD patients whose medications are no longer giving them a good quality of life can find relief in therapies such as deep brain stimulation (DBS). "When side effects prevent higher doses or the response to medications isn't sustained and the symptoms of PD are interfering with what you want to do on a daily basis, then it's time to think about DBS," says William Marks, M.D., a neurologist at the University of California. An electrode is inserted into specific regions of the brain and attached through a wire to a device that, much like a cardiac pacemaker, sits under the skin

in the patient's chest. The brain is stimulated with electrical pulses that can eliminate many signs of PD. By Melissa Ward, New Hope for Parkinson's NL

Nutrition and PD Medicines

Why are PD medications a concern?

In some people, the agonists, such as Requip® (ropinerole), Mirapex® (pramipexole), and Permax® (pergolide) can cause fluid retention, known as edema. Edema is worsened by salt intake; there is an old saying that "Water follows salt." This means that when you eat too much salt, the sodium accumulates in the tissues. The body then floods the tissues with water to protect against the irritating sodium. Often, the edema occurs in the feet, ankles, and/or lower legs; but it can occur in any part of the body. Swollen feet and ankles are uncomfortable; and besides this, edema can elevate blood pressure.

Parties, buffets, and appetizers, and many of these special party foods are high in salt. If edema is a problem, ask in advance if the host can provide some low-sodium foods. Avoid corned beef, pastrami, bacon, ham, soy sauce, pickles, olives, and other very salty foods. Instead choose plain roast meats and poultry, fresh vegetables and fruits, dips flavored with herbs, garlic, and other non-salt seasonings, and unsalted nuts and pretzels. **(Note: Water pills will not reduce edema caused by agonists.)**

Levodopa and protein

Many people with PD use medications that contain levodopa — Sinemet®, Stalevo®, Madopar®, Larodopa®, L-Dopa®, Dopar®, and Atamet®. These medications are broken down in the stomach and pass into the small intestine where they are absorbed into the bloodstream. Proteins in foods are also broken down in the stomach and pass into the small intestine, where, as amino acids, they too are absorbed into the bloodstream. The problem is that the levodopa must compete for absorption with these amino acids; and since the pill is very small, and the meals are much larger, the aminos win out. The levodopa never reaches the brain, and therefore cannot do its job of controlling PD symptoms. When using foods rich in protein such as turkey, ham, chicken, beef, lamb, liver, eggnog, cheese

for parties it's tempting to nibble throughout the day as these dishes are being prepared and set out. But if you nibble too much protein, you may find that when you take your levodopa, the medication just doesn't take effect. It can't — there's too much protein blocking its absorption. Controlled-release or extended-release medications, such as Sinemet CR and Madopar HBS, were designed so that they could be taken with meals. They take longer to become effective than regular Sinemet and Madopar, however; and taking them with meals adds to the absorption time. Also, eating large amounts of protein, or eating protein between meals, can affect the absorption of controlled-release levodopa medications. So if you are spending a long time "off" (time when medications are not working), try taking the Sinemet CR or Madopar HBS about 30 minutes before meals to see if that helps its absorption.

A word about fat

Many foods are also rich in fat — dips, chocolates, doughnuts, cookies, pies, etc - and people with PD can enjoy all of these. However, some folks with PD develop a condition known as gastroparesis, or slowed stomach emptying. This means that foods take longer to empty from the stomach than normal. When foods stay in the stomach for a very long time, the next dose of PD medications may have to remain in the stomach, too; it cannot reach the small intestine because the food is blocking the way. This means that PD symptoms won't be controlled.

Fat takes much longer to clear the stomach than carbohydrates and proteins; so dishes that are rich in fat will remain in the stomach much longer than low-fat foods, especially if gastroparesis is present. Signs of slowed stomach emptying include abdominal bloating, heartburn or acid reflux, delayed uptake of PD medications, and feeling full after just a few bites of food. If gastroparesis is present, it's a good idea to eat those rich favorite foods in small amounts; a slowed stomach can handle a tiny portion of fatty food much better.

Kathrynne Holden, MS, RD

Treating the Disordered Speech of People with PD

For many individuals with PD, the loss of their strong voice affects their lives greatly as they lose their ability to talk with loved ones, use their voices effectively in daily living and interact proactively with society. Without question, the loss of this ability to communicate has a significant impact on the quality of their lives. Over the last ten years, LSVT®, an effective speech treatment, has been developed in response to the speech disorders attributable to PD. People with PD who received LSVT® improved their speech, vocal loudness, intonation and voice quality, and maintained these improvements up to two years after treatment. Recent research studies, supported by the NIH and the National Institute for Deafness and Other Communication Disorders (NIDCD), have documented improvements in the common problems of disordered articulation, facial expression and swallowing in individuals with PD following LSVT®.

The LSVT Foundation has produced a videotape that individuals may use at home to do voice exercises as part of the LSVT method. Called the LSVT® Alive! Patient Homework Helper video, the viewer is prompted through a series of daily speech exercises that will help the individual maintain and enhance the improvements in their voice after the therapy sessions with a certified LSVT® clinician.

Additional information about LSVT® is available at the LSVT® website — www.lsvt.org or by phone, 1-888-606-5788; by fax, 1-520-615-8559; or by email: LSVTVP@aol.com.

Parkinson's Report, Fall 2003

Dry Mouth Relief

A quick spray of Salivart provides immediate relief from dry mouth. A single application facilitates chewing, swallowing and speaking. Salivart contains no irritating alcohol or glycerin. No prescription is required. Check your local pharmacy or order direct by calling 1-800-321-9348 or going to www.gebauerco.com.

Fibromyalgia AWARE, Oct 2003

Read All About It

Guidelines on living life to the fullest for PWP's. The title "*Hope-Four Keys to a Better Quality of Life for Parkinson's People*", is a perfect fit to a useful new book. It is written especially for those who are searching for hope in the atmosphere of anxiety that is commonly experienced by people who have been recently diagnosed with PD. It also serves as a helpful reminder of how someone who has endured PD for many years can achieve and maintain a better quality of life.

"Hope" adds to the PD literature because it goes beyond describing the disease by humanizing it. The writing is succinct and easy to read. It outlines four keys to hope: Help, Optimism, Physician, and Exercise.

"Hope" is full of thoughts on how to help new PD patients reach a point where they can find a way to live each day to its fullest. "Hope", 2002, can be ordered from the Northwest Parkinson's Foundation, by calling 1-425-746-5556 or at www.nwpcf.org. The price is \$12.

PDF Summer 03

Patient Transportation

Do you need help getting to the Dr?

-Within Bexar County, you can call Elderly/Disabled Support Services at 207-6680, M-F, 7:45-4:30, three to five days in advance to schedule transportation. They transport wheelchairs and scooters and pick patients up at their curbside.

-In Blanco or Boerne Counties, you can call Blanco County Transportation at 830-796-7758. A minimum of 24 hour notice is required for transportation arrangements.

"One Day at a Time"

Live one day at a time
Then recollect each hour;
Select a single thing of good
And pluck it for a flower.

Like lilies of the field,
Decline to dread tomorrow.
They stand all day in proud array
Not wallowing in sorrow.

Jean Wood, *A Voice for the Caregiver*

Count Your Blessings

1. Understand you have a choice. You choose your own attitude.
2. Avoid negative words and thoughts.
3. Study the thoughts and writings of positive people.
4. Tell people what they are doing is right (that includes talking to yourself).
5. Celebrate victory – don't dwell on defeat.
6. Count your blessings every day.

NPF, Fall 2003

Emotional Problems in PD

People with chronic, disabling illnesses like PD have a high incidence of emotional problems that a caregiver needs to recognize. People with PD suffer more frequently from depression and may harbor fears of abandonment. Some react to their disease with periods of hostility and many suffer from nagging fears such as:

- How rapidly will my PD progress?
- Will I be able to continue to work?
- Will I become completely disabled/dependent?
- Will my life span be shortened? These particular fears, often passed off to the caregiver, cause stress that can aggravate the disease. Unfortunately, no one can answer these questions with any degree of accuracy. Medications can also alter the course of the disease and make its outcome even more unpredictable. What is not emphasized enough is that nearly every PD patient can reduce stress and improve the quality of his or her life through:
 - Knowledge
 - A positive attitude
 - Healthy emotional and physical activity
 - Remaining fiercely independent for as long as possible.

The Spouse as Caregiver

P D, even in its early stages, can affect balance, manual dexterity, muscle strength and endurance. Therefore, some degree of help from a caregiver may be needed early on. As the PD progresses, even greater demands and stress are placed on the caregiver. Therefore, care of the caregiver needs to be a primary consideration when we address PD.

The caregiver, at least in the beginning, is usually the spouse. Roles in the relationship usually have to change. The well spouse often becomes the major support for the patient and the family. The spouse caregiver's main role is to give the patient physical and emotional support while at the same time striving to maintain his or her own emotional integrity. Feeling sorry for oneself or frequent expressions of pity for the victim does not help and only stifles the coping process.

The caregiver may face a variety of stressful emotional reactions from the patient:

- Lack of motivation and reduced ability to concentrate.
- Depression and withdrawal.
- Is defensive or in denial.
- Becomes hostile toward everyone, including the caregiver.
- Becomes increasingly more dependent and helpless.

On the other hand, the patient may assume a different or less stressful posture. He or she might:

- Accept the situation and attempt to regain self-control.
- Adjust to the changes in spousal roles.
- Remain upbeat most of the time.
- Maintain social ties to friends and family.

What the caregiver encounters, the symptoms of which may vary considerably, depends upon the often unique and changing personality of the patient prompted by their disease. The caregiver needs to try to understand and adapt to these different personality changes, in order to best care for the patient.

Ten Things Caregivers Should Know

1. Understand the importance of taking care of yourself, too.
2. Realize it is normal to experience a range of feelings – anger, sadness, loneliness, guilt and resentment. Try to see humor in the situation. Laughter is good medicine!
3. Learn constructive ways to channel emotions – exercise, talk with friends, practice relaxation techniques.
4. Practice positive talk.
5. Recognize depression and get help for it.
6. Arrange to make time for yourself, your interests and friends.

7. Attend support groups and talk about your problems.
8. Learn how to face your loved one's physical challenges. Do not allow the patient to be manipulative and demanding.
9. Let a loved one do as much as possible while he/she is still able.
10. Deepen your faith and spirituality.

Parkinson's Report, Fall 2003

A Study of Wheeled and Standard Walkers in PD Patients with Gait Freezing

Background. Although numerous walking devices are used clinically, their relative effects on freezing and walking speed have never been systematically tested. The authors were particularly motivated to conduct this study, because so many patients use walkers that were self-prescribed.

Methods. Nineteen PD patients (14 non-demented) walked under three conditions in random order: unassisted walking, standard walker, and wheeled walker. Patients walked up to 3 times in each condition through a standard course that included rising from a chair, walking through a doorway, straightway walking, pivoting, and return. Total walking time, freezing time and number of freezes were compared for the three conditions using mixed models (walking time) and Friedman's test (freezing). The wheeled walker was further studied by comparing the effect of an attached laser that projected a bar of light on the floor as a visual walking cue.

Results. Use of either type of device significantly slowed walking compared to unassisted walking. Neither walker reduced freezing. The standard walker increased freezing, and the wheeled walker had no effect on freezing.

Conclusions: Though walkers may stabilize patients and increase confidence, PD patients walk more slowly when using them, without reducing freezing. The data for the study data clearly demonstrate that neither type of walker nor the use of a laser line added to a wheeled walker is useful as a tool to overcome freezing. In fact, standard walkers aggravated freezing. With these findings, the authors confidently discourage PD patients with predominant freezing

from utilizing a non wheeled walker to overcome this problem. Because the wheeled walker was intermediate for walking time and does not aggravate freezing, if walkers are used for these subjects, this type of walker should be favored. The study does not establish the mechanism underlying the walker-induced exacerbation of freezing with the standard walker. In the authors view, the most likely explanation is that the walker acts as a visual obstacle. Because doorways, narrow passages and other restricting environmental elements typically aggravate freezing, the presence of the standard, non wheeled, walker may have contributed to the poor outcome on freezing by providing a "negative" clue.

Comment: This study addresses an important issue: when a person with PD needs a walker which one should he or she get. The wheeled walker appears preferable especially as it does NOT aggravate freezing (although it does not help freezing). A factor NOT emphasized in the study was the height of the walker. A walker that is too low forces a person with PD to bend further at the waist and this in turn may slow walking further.

This article was modified by Dr. Abraham Lieberman to make it more readable for patients with PD, their relatives, and friends. It is only for educational use. The article appeared in *Parkinsonism & Related Disorders*, volume 10, 2003, pg 9. The lead author is Esther Cubo

PD Progression

There are at birth approximately 400,000 nerve cells in the substantia nigra. All of us lose about 2000 cells per year. In a person with PD, the rate of loss increases to 5000 to 10,000 cells per year. When you lose 240,000 cells you develop the first symptoms of PD. The older you are the less reserve you have and the more rapidly the disorder will progress.

The above is an approximation of what happens in a given person. Based on age of onset, current age, stage of the disease and prior progression, a prediction of future individual progression can be made, but it is only a prediction. Everyone progresses differently so a common prediction of progression can't be made for the population as a whole.

NPF AsktheDr

Cause and Number of PD Patients

We don't know the cause of PD, but spousal PD (husband and wife with PD) is relatively uncommon. When I was in New York I had 3 husbands/wives with PD from among 2000 patients. This is reasonably good evidence that PD is not an infectious disorder, and may not be an environmental disorder because the husband and wife normally share the same environment. Generally, the older the population surveyed the higher the number of people with PD. No one knows the exact number of people with PD, but NPF uses 3500 PD patients per 1,000,000 people, which is 3.5 patients per 1,000 people. This number is based on a study done using the sales of sinemet, which is used only in PD, and on surveys done at the Mayo Clinic in Rochester.

Dr Lieberman, AsktheDr

Ask For Help

Why is it so hard to ask for help? What's a good response to the statement, "Call me if you need me?" How is it that despite the fact we are drowning in responsibility or are really confused about what our next step ought to be, we often respond "no thanks" when help is offered? Asking for and accepting help is a complex issue. Obviously we first need to recognize that having some help can make a real difference to our loved one's well-being and ours as well. Then we need to figure out what do we actually need help with and what kind of help are we willing to accept. There are of course the practical issues regarding paid help, versus friendly help. If this just sounds like more work, another list of things to do, know that it doesn't have to be an overwhelming task, but rather just a way to organize thoughts and information you may already have.

Just as with respite, which is designed to give you a relaxing break from your responsibilities, having help can restore your equilibrium because removing some of the responsibility from your shoulders will lessen your stress. It will also enable you to be a more peaceful and effective caregiver because you won't feel so much alone; and that's got to make you a happier and hopefully healthier person. It is precisely because

you do care that getting some help when you need it is important.

Not all family caregivers need help, of course. If your husband is relatively independent despite his disability, or your dad just needs a daily reminder to take his medications, then your caregiving responsibilities may well be very manageable and not a concern at this time. But for those of us that need to help loved ones with personal care on a daily basis, or are part of the sandwich generation caring for elders as well as our own kids, or are just feeling generally overwhelmed by caregiving issues, having help can make a big difference.

The Benefits of Getting Help

- It can lessen your sense of isolation knowing that other people have an idea of what you are dealing with and are willing to be there for you when needed.
- It can move the dial on your "worry meter" down to a safe level.
- It can encourage your loved one to be more independent.
- It can give you more confidence in your ability to manage your caregiving responsibilities.
- It can increase your ability to think creatively and expand the options you now have available to you. To my way of thinking, those are pretty good benefits indeed.

Caregiving is work

As family caregivers we are adding work to our already busy lives, and even though most of us very willingly and lovingly take on this added responsibility, it is important to remember that it is just that, more responsibility and more work. So what happens to all of the other work you were previously doing? Cooking and cleaning and shopping, being a carpool mom for the kids, walking the dog, holding down a job, paying the bills, none of these are going away.

If you can find even one person or one service that can reduce your regular workload by either taking over all or part of one of your regular chores, you'll have more time for your caregiving, and less stress bearing down on you. If you can find a person or service that can help with your specific caregiving responsibilities, you'll be in a better position to meet your non-caregiving responsibilities. Finding help is often difficult for emotional, financial, and geographic reasons, but

it can make a big difference in your ability to be an effective caregiver, it can make a big difference in your loved one's well being, and it can make a difference in your own well being and that of other family members as well. It's worth the effort.

By Suzanne Mintz (This article is adapted from Ms. Mintz's book, Love, Honor, & Value — A Family Caregiver Speaks Out About the Choices and Challenges of Caregiving (Capital Books 2002))

MEMORIALS

In Memory of Hilda Frees

Robert & Geraldine Kerr

In Memory of Glen Bliss, Jr

Mary Gorden

Jean & Pierrette Riou

In Memory of Staley Mims

Ella Verne & Whitley Smith

In Memory of Ross Dunham

Carlos & Sybil Jones

Pierce D. Thompson

Fatio & Elise Dunham

Lyman & JoAnne Kirkwood

Jim & Marje Leonard

Bill & Gay Phillips

Talmadge S. Skinner

Elizabeth H. Wagner

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Ruth Priddy

Catherine Craig

Jeanne Burhans

St. Augustine Easter Week Festival

Bill Sickert

Barbara Smith Leopard

Mr & Mrs Frank Neely

Roy Holmberg

William & Wilma Morrissey

David K & Susanne L Jackson

Jany's & Jim Leary

Annette & Herbert Wiles

Mr & Mrs Aubrey James