

Providing Education and Support for those with Parkinson's Disease, their families and friends, caregivers and healthcare providers in the greater Austin Community.



CAPITAL AREA PARKINSON'S SOCIETY

A 501(3)(C) Non-Profit
(512) 459-9876

www.capitalareaparkinsons.org

April, 2007

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April Meeting

The next meeting of CAPS will be held Saturday, April 14, 2007 at 2:00 pm in the Mc Fadden Auditorium at Seton Main Hospital.

Parking is available in the garage at the south entrance. Free parking vouchers are available at the meeting.

In this month's session, we'll be meetin' and greetin' with some of the fine folks from Austin Groups for the Elderly. [AGE](#) (as it's also known) is a 21-year-old non-profit organization built around a mission of "empowering caregivers, the elderly and their families through education, advocacy, resources and support."

One aspect of AGE's approach to their mission - called "essentially one stop shopping for caregivers" by [Judy Maggio](#) of KEYE TV - is the [Caregiver Resource Center](#) (CRC). At this meeting we'll have Eva Church, CRC's director, on hand to fill us in on the CRC and answer

our questions. We'll also be hearing about [Elderhaven Adult Day Care](#), "a safe, secure and stimulating environment for adults who need assistance with daily living skills." It promises to be an interesting session. Don't miss it!

March Meeting Update

Ok, I have to admit it: I had some reservations about attending an hour long discussion of [Capital Metro's](#) bus service. I mean, how interesting could *that* be, really?

Remarkably interesting, as it turned out, because Nancy Crowther made it that way. A seventeen-year Accessible Transportation Specialist for Capital Metro, Ms. Crowther's combination of wit, wisdom and humor (backed by a deep knowledge of her material) made March's session as informative as it was enjoyable. Our warmest thanks go out to her, and to CapMetro for making her available to us. She's a jewel!



The Learning Curve

Blah, Blah, Blogging

It's 'way-too-early morning, and we're sitting around a table strewn with the remnants of breakfast. Newspaper rustles. "Hmms" and "Huhs" are seeds for snippets of discussion as this news item or that catches our attention. And then: "Tell me again: what's a blog?"

What, indeed. This subject comes up so often probably because a) it's a hot topic, adored by the news media and b) I've always explained it poorly, if at all.

The concept is simple enough: a WebLog, or 'blog' for short, is defined by Wikipedia (an online encyclopedia) as "a user-generated website where entries are made in journal style and displayed in a reverse chronological order." In other words, blogs are like diaries, where people write about things that interest them . . . and then make their words available on the Internet for the whole world to read.

It's the "for the whole world to read" that's the tricky part. Diaries have locks to keep little brothers and suchlike from reading them, right? Then why would anyone in his or her right mind go out of the way to put one on the World Wide Web?

There are a number of different answers to that question, but I think it all boils down to a subtle, powerful fact about the Internet, this "place" where millions of computers connect to each other: there's *community* out there. The 'S' in CAPS stands for *society*. It's about being social, about getting together to share information we've learned about Parkinson's Disease. Now imagine a CAPS with a bazillion members, each as close as your keyboard, where you "talk" about your day, your frustrations, your victories and setbacks and others listen and learn and leave comments, share their own experiences, their hopes and dreams and pain. That, Gentle Reader, is a blog.

There's one key difference between the "blogosphere" and an actual, physical Society where people meet face to face, and that's anonymity. Oh, you could wear a mask to CAPS meetings and never tell anyone your name, but how likely is that to happen? Well, on the Internet, that's the norm. Out there people use "screen names," similar to the "handles" that were used back when CB radio was all the rage (and yes, I'm *so* dating myself). Many find it easier to talk openly when they're disguised, and I've been told by several bloggers that they blog just to get stuff down, to help them sort things out. They find that writing for an audience forces them to look more deeply at what they're saying, to organize their thoughts in ways they might not have done otherwise. New insights have been claimed.

A note on anonymity: it's a double edged blade: bad people can hide behind cute monikers, and care must be taken to avoid giving too much away. First names work, but Social Security or credit card numbers are definite no-nos.

If you're interested in becoming a blogger, there are lots of places "out there" to get started. Many make the process as simple as typing and sending an email. For more information, try searching the Web for "[blogs](#)" - or have your granddaughter show you how. Just be prepared for a learning curve . . .

Caregiver's Corner

Back in March, I got a letter from Lois Rice, President of CAPS (and a darned nice lady). "You inspired me to contribute my 2-cents worth," she began, "from the position of a recovering caregiver." (Huh?) "Yes, 'recovering caregiver'."

I was hooked. "Caregiving can become a total life," she continued, "like an addiction. One slips into it slowly, gradually adding one thing and then another until it becomes one's total life. So this is a 'do as I say, not as I did' commentary."

She told me I could edit, add, subtract, whatever, as needed, and that I could use this anytime as "filler." I've exercised editorial privilege *not* to edit. What follows is not added to (besides the bullets) or subtracted from, and most definitely not filler. I think you'll see why.

Some things I have learned:

- Train your loved one to accept help from several people. Do not accept "You do it just the way I like it". There will be times when others will need to provide the care.
- Have a list of care instructions posted on the refrigerator or readily available for other caregivers.
- Post emergency information on the refrigerator.... medications, doctors' names and addresses, persons to contact, all pertinent medical information, etc.
- Inform your local EMTs about who lives at your address and what the needs are. They can be prepared when you call them.
- Keep care directives up to date, and where they are easily accessible in an emergency.
- Get your "affairs in order". Brings much peace of mind.
- Use your resources. Don't say "We're doing fine. We don't need anything. PEOPLE REALLY DO WANT TO HELP, TO BE USEFUL. You can say, "At the moment, we're doing fine, however....."
 - _____ really enjoys your visits. Please drop by soon, or drop by on (specific day).
 - _____ enjoys (specific activity) with you
 - I just never seem to get the yard raked, or those limbs trimmed, or something dusted, or
 - You make a super _____ casserole. We would really enjoy one.
 - Could you take _____ for a ride, just to look at _____ or just to get him/her out of the house for a while? Some new scenery would really be good.
 - Could you take my car for an oil change, inspection, to the car wash, etc?
 - I need a few things from the grocery. Could you get these when you go shopping?
 - Could you stay with _____ while I go _____ ? Not only going out, even taking a nap.
 - Let's eat a meal together at _____ .
- Be visible. Become acquainted with your neighbors. Maintain memberships, especially religious affiliations. Nearly every faith group practices some form of outreach to members, and may provide help including visitations, food, transportation, comfort, and encouragement. I know of one church that has a committee that will provide physical help for a home such a changing a light bulb, building a wheelchair ramp, repairs, computer assistance, almost anything.
- I know the advice books say to continue all your old activities. Doesn't work. One needs to pick and choose. Do keep some activities. AVOID ISOLATION.
- Exercise, Exercise, Exercise. You, too. You need it to work out tension and stress, and for your fitness. This is an important part of your "time for yourself".
- Educate yourselves all you can about Parkinsons Disease. This enables you to make better decisions, and keeps you from being surprised as events unfold. You are already doing one thing by joining CAPS, reading this newsletter, and attending meetings. Persons who participate in the operation of this support group receive even another dividend from the satisfaction of their service.
- KEEP YOUR MEDICAL APPOINTMENTS. MAINTAIN YOUR HEALTH. OTHERWISE THERE WILL BE TWO PERSONS IN NEED OF CARE.
- Guard against depression. It is common for caregivers, too. Talk to your doctor if you think you are becoming depressed.

- Keep a "list in your pocket" so when someone offers to help, you have some ideas of ways you can use their help.
- Use RESPITE CARE. Medicare will pay for it. Check it out to learn how it can be used. This is a way to get a break for a few days. Use it BEFORE you are completely worn out.
- Get your rest. Be sure you get to bed on time.
- One speaker once suggested that you keep a journal, and your loved one keep a journal, each day writing observations of how they felt emotionally, physically, etc., even how you feel. Very useful in noticing gradual changes, referring back to "when it started". Not a long essay. Just a few sentences.
- If you can, hire some help.

"After Stan died, I realized I had become a zombie, moving from task to task to somehow 'get through' each day.

"As I gradually recuperated after his funeral, people started telling me, 'You look so much better.' Some frankly told me, 'You were looking terrible.' It takes a long time to build yourself back and develop an 'after Parkinson's' life."

Thank you, Lois. By sharing this, you may have helped some of us other folks avoid becoming "recovering caregivers."

Support Group Meetings

Austin, TX Support Group: The Austin Parkinson's Disease Support Group meets on the **3rd Friday of each month, from 10:00 - 11:00 AM**. Location: Parsons House, 1130 Camino La Costa, Austin. For more information, please call Jaime Eyer 512-454-5502 or email [Susie Lightfoot Scherr](#) or [Kitty Hoskins](#).

Bastrop, TX Support Group: The Bastrop Parkinson's Disease Support Group meets on the **4th Thursday of each month, from 2:30 - 3:30 PM**. Location: Argent Court, 508 Old Austin Hwy, Bastrop. For more information, please call Dawn Smith at 512-321-9500 or email Susie Lightfoot Scherr or Kitty Hoskins.

Burnet, TX Support Group: The Burnet PD Support Group meets the **2nd Tuesday of each month, from 1:00 - 2:30 PM**. Location: Take Aim Team Training Center, 401 Buchanan Drive (Hwy 29), Burnet. For more information, please call 512-756-4949 or email Susie Lightfoot Scherr or Kitty Hoskins.

April Young Onset Group Meeting

The Young Onset Group meeting will be held Sunday, April 21st, 2007 at 3:00 PM at the Red Lobster, 109 W. Anderson. For more information, contact James Shrader at 671-3067 or at mr12stringjms@aol.com.

About the Newsletter Staff

This newsletter is assembled monthly - usually late - by Tom Fisher, AKA jumpstart5@sbcglobal.net, and opinions expressed herein are not necessarily those of CAPS leadership, advisors or members (though I hope they at least come close). Any and all suggestions and comments for its improvement will be graciously accepted.

