

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

<http://www.capitalareaparkinsons.org>

February, 2007

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February Meeting

The next meeting of CAPS will be held Saturday, February 10, 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.

This month, our speaker will be Michelle Ciucci, PhD, CCC-SLP. Dr. Ciucci is a post-doctoral fellow at the Institute for Neuroscience and a lecturer in the Department of Communication Sciences and Disorders at the University of Texas. She researches the role of dopamine and the mechanism behind behavioral treatment for speech/voice/swallowing disorders in PD and also collaborates with Dr. Izor on deep brain stimulation research. She is a certified speech-language pathologist and teaches graduate students about diagnosis and

treatment of speech disorders. She has served on the Board of

Directors for the Arizona Chapter of the American Parkinson Disease Association and looks forward to being involved with CAPS. Her talk will focus on managing speech, voice, and swallowing disorders in Parkinson Disease.

January Meeting Update

Our thanks go out to Dr. Tom Hill, who presented information on newer PD drugs, listing many attributes and side effects. The future treatment of PD looks promising with early detection being most important. He discussed several different treatment strategies, progress of Research and Development, and shared some insight into the lively discussions going on between doctors in Texas and the country at large.

As always, it was a pleasure to have Dr. Hill grace our meeting!



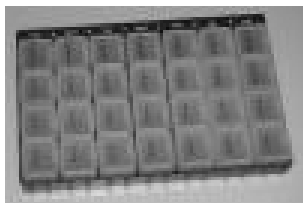
New Column: The Learning Curve

Parkinson's patients, caregivers and families are faced with a complex situation. There is so much to learn, and a lot of it we have to make up as we go along. That's one good reason for being a member of an organization like CAPS: to learn from others in our shoes, those who face similar challenges.

As part of the expanded newsletter, I hope to help in the sharing process. It's what The Learning Curve column is all about. So, with no further ado, let's take a look at a problem I encountered early on. I call this one "MED-itation."

I had never seen so many pills as those my mother-in-law was taking when she joined us in Austin. Over time, the drug count and the schedule grew, and eventually I offered to take over the process. She was already using a pill sorter, one of those boxes with seven rows and four columns of compartments (a week of days across and three meals and bedtime down). I also had a list of all her meds and how many of what she should take each day. It was slow going, working down the list, dropping a pill in each yawning hole. Often, the phone would ring or there was a knock at the door, and when I came back, it was pretty much time to start over.

After a couple weeks of this, it was apparent that there had to be a better way. After I scratched my head a bit, it dawned on me: the layout of the pill box looked like the rows and columns of a spreadsheet. A quick trip to the computer, a little typing and the solution was ready. (You can do the same thing with pen and paper.)



Across the top row of the matrix, I put the names of the pills, and down the side went the times they were to be taken. Then, where a pill column intersected a row labeled with the time she takes that pill, I put a dot to tell me one of those pills goes into that box.

The result looked like this:

A1		Updated 2/1/07											
	A	B	C	D	E	F	G	H	I	J	K	L	M
		Pill #1	Pill #2	Pill #3	Pill #4	Pill #5	Pill #6	Pill #7	Pill #8	Pill #9	Pill #10	Pill #11	Pill #12
1	Updated 2/1/07												
2	Breakfast	•	½	•	•	•	•						
3	Lunch		½					•	•	•	•	•	
4	Dinner							•					•

(Note: I use the actual pill names across the top. In the interest of Mom's privacy, I've replaced these with Pill #s for this example.)

It worked like a champ. Every Sunday, I start across the list, working from left to right. In each compartment of the Breakfast row goes a pill #1, ½ of a pill #2, and pills 3 through 6. Then I work my way across the lunch and supper rows and I'm finished. To make sure interruptions won't derail the process, I move each bottle to a holding area as I put its contents into the box, and then put all the bottles back on their shelf when I'm finished. Simple as that.

A side benefit of this matrix is that it gave me a handy reference chart to use when looking for drug interactions. Some pills don't get along with others, and while every doctor Mom sees has a complete list of her meds and will hopefully make sure new prescriptions won't interact with old ones, I wanted to sort her pills so that at least no interacting drugs were taken at the same time. With my new list in hand, I used an online interaction checker and wound up rescheduling several of them. Note: be sure to talk with your doctor(s) about any interactions you find. They're busy people, and sometimes things slip by.

So there you have it. You've probably already figured out something else that works for you, but I'm hoping that for at least a couple of you, this will be of some help. Have you faced a challenge in your dealings with PD and come up with a solution others might find useful? Would you care to share it? If so, please give me a call at (512) 282-9420, or email me at jumpstart5@sbcglobal.net.

Tom Fisher



New Column: Caregivers Corner

Greetings, fellow caregivers! This column is for those of us that devote our time and energies to ... well, giving care. It's a big job, and in many cases, it's 24-by-7. Usually, it's unexpected, unplanned and hence, not something we're prepared for. While we can't do much about expectations or planning, we may be able to help with the preparation. (Or maybe that should be *post*-peration, since we're already here and doing it.)

There's nothing simple about an occupation that delves so deeply into intimate facets of another's life, be it a friend's or an elderly parent's; it takes a lot of getting used to. Then there's the exposure to a reality we seldom consider: the vulnerabilities of the human body. We grew up invincible, and despite rumors to the contrary, we were going to live forever. Watching helplessly as a loved one deteriorates can be a rough wakeup. Now mix in the myriad other details involved, and it's the old Clare Booth Luce quip: "No good deed goes unpunished."

According to the U.S. Department of Health and Human Services Administration on Aging (USDHHSAA), and I quote:

- Caregivers care for themselves less than non-caregivers do
- Approximately half of all caregivers show clinical signs of depression
- Older caregiving spouses are at higher risk of dying than non-caregivers of the same age
- Younger "baby boomers" - those dealing simultaneously with parents, children and career-are also at increased risk for illness

Now don't get me wrong, I'm not trying to dissuade you from this admirable, caring task you've undertaken: to paraphrase Martha Stewart, it's a Great Thing. What I *am* trying to do is to make you aware that if you've been neglecting your own health, it's a) not uncommon, b) not perverse and c) something you should think about carefully.

Taking the time and money to take care of your self probably sounds selfish. Nothing could be farther from the truth. Letting your self go while you focus on others' needs serves neither of you well. If a caregiver gets sick, the repercussions can be greater than those suffered by a non-caregiver. Again, to quote the USDHHSAA, you may:

- Infect your loved one
- Make caregiving errors or questionable decisions
- Have to resort to more costly alternatives for care
- Be separated from your loved one if you need to be hospitalized.

In other words, if you get sick, what was once a difficult situation becomes even more difficult.

Oh, great. So now I should make a belated New Year's resolution to take better care of myself, right? Go join a gym, maybe? Take mega vitamins every day? Join Weight Watchers? Sign up for a marathon?

Probably not so much all at once, though any of those things may be appropriate; that's up to you. What you might want to consider as a first step is much simpler than that. Did you get your flu shot this year? How about pneumonia? When did you take your last tetanus booster? Getting vaccinated is a simple, (relatively) painless way to take a first step toward better health - or at least preventing avoidable, serious health problems.

It's certainly something to think about. For more information, go to The Family Caregiver Alliance Website at

<http://www.caregiver.org/caregiver/jsp/home.jsp>.

Do you have tricks, tips or strategies you've learned or devised to help you shoulder the caregiver's load? How do you manage your health? Where do you need help? Would you care to share something with others out there in Caregiver Land? As with the Learning Curve column, please, give me a shout.

Tom



To the Freddy Powers PF: Our Thanks

We'd like to express our warmest appreciation to the Freddy Powers Parkinson's Foundation (<http://www.freddypowers.org/>), who donated \$4500 to CAPS back in December! Thank you, and rest assured it will be put to good use!

The Next Three CAPS Meetings

Date:	Topic:	Speaker:
March 17 th	To Be Determined (TBD)	TBD
April 14 th	TBD	TBD
May 12 th	TBD	TBD

Please note that both the April and May meetings take place the *second* Saturday of the month rather than the third. Topic and speaker information will be added to the calendar page of the CAPS Website as it becomes available.

Support Group Meetings

Parsons House Retirement Center will have all PD Support Meetings the 3rd Friday of each month from 1:00 - 2:30PM. For more information, go to the CAPS Web site home page and click the Parsons House Parkinson's Disease Support Group link.

New support group meetings have been established at Argent Court, an assisted living community at 508 Old Austin Highway in Bastrop. Meetings will be held the 4th Thursday of each month in the activity room. For more information, contact Susie Lightfoot Scherr at 512-345-1380.

Board Of Directors Meetings

The CAPS Board of Directors will meet at 2:00 PM, Tuesday February 13th in the Parsons House Chapel.

February Young Onset Group Meeting

The Young Onset Group meeting will be held Sunday, February 18th, 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, for better or worse, by Tom Fisher. Any and all suggestions and comments will be appreciated.

