



Parkinson Pathfinder

THE NEWSLETTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION
INFORMATION AND REFERRAL CENTER OF WASHINGTON

Summer 2009

Sexuality, Intimacy and Parkinson's Disease

By Kristoffer Rhodes PhD, Physical, Medical and Rehabilitation - Virginia Mason Medical Center

Most people familiar with Parkinson's disease (PD) are aware of the movement and motor symptoms that classify this as a neurological condition. Other prominent and all too frequent symptoms, however, are discussed less often. These include depression, anxiety, behavioral disturbances and personality changes. Rarely discussed are the changes in sexual functioning and intimacy that frequently accompany PD. As many as 68% of men and 88% of women with PD experience decreased libido, problems with sexual functioning and a sense of decreased intimacy with their partner. A smaller, but still significant percentage experience increased sexual behavior that can be incredibly disruptive and difficult to talk about. Despite these staggering figures, the barriers to discussing these problems persist, including lack of quality research in the area, taboos about sexuality in the elderly and those with neurological disease, and feelings of discomfort when talking about difficult topics. This article provides a starting point for patients, partners and providers to start talking about ways to improve sexuality and intimacy for those affected by Parkinson's.

There are many factors that may lead to changes in intimacy and sexuality in couples dealing with Parkinson's disease. Among the main predictors of sexual dysfunction and declines in perceived intimacy are increased age and severity of the disease and its symptoms. These include motor impairments such as rigidity and tremor that can lead to impaired mobility in bed. There may also be changes in appearance such as sweating, drooling, changes in body odor due to the

disease or medications, as well as gait disturbance. Facial masking and decreased expressiveness may make it difficult to read affection and desire. Sleep disturbances may lead to bed separation, thus making intimacy less spontaneous and infrequent. It should be noted that previous sexual problems and depression are also two of the major factors that impair intimacy and function, as are the presence of other health conditions, such as diabetes and heart problems. As if all of these things weren't enough, both those with PD and their caregivers typically experience significant fatigue and changes in roles that disrupt the usual patterns and venues for intimacy. So what can couples do to begin to reclaim the intimate parts of their relationships?

The first step is attempting to clarify your concerns and feelings in your own mind and then talking about them with your partner. Recognize and address the emotional stresses of the illness, caregiving, and care-receiving. A good place to start may be to spend some time thinking about the following questions: "What do I need? What do I want? What's missing? What's working?" A frequent and sometimes sizeable barrier to discussing intimacy and sexuality can be our own internal discomfort with the topic. There may be internally held beliefs that "good boys and girls don't talk about these things." Rest assured that they indeed do. The anticipatory anxiety and fears of discomfort are often worse than any actual embarrassment that may arise when partners find the courage to begin the

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APDA Information and Referral Center

Neurology, S-127
 1666 S. Columbian Way
 Seattle, WA 98108
 Phone: 206.277.5516
 Fax: 206.277.4342
 Hours: M-F 10 am - 3 pm
 apda@u.washington.edu

For information packets, literature, or other Parkinson related issues, please contact the Information and Referral Center at the above address or visit our website at www.waparkinsons.org

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 evedavis@gmail.com
 425-443-8269

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 To The Board Address*

President's Report

Congratulations to Evie Davis, Suzanne Cameron and the many other people who put on the fourth annual APDA Magic of Hope Dinner Auction on May 9th. This year's event was great fun. The others have been, too, but this one was special. The location was very good (the Seattle Renaissance Hotel). The auctioneer (Rene Spatz) was excellent and so were the auction items. Three hundred attendees and \$106,000 raised were very good numbers given the economy we're in. All in all it was just a wonderful night. Thanks to everyone who attended, procured auction items, bought tables, volunteered the night of the event and spent money .

Continuing APDA activities include the very successful Taxi Voucher program (supported by the auction) which is expanding geographically to include all of King County as far north as Everett. And, of course, demand remains strong for the DVD, Straight Talk and Honest Hope, now out in its second edition.

The Executive Committee is in the process of interviewing candidates for the I&R Coordinator position made available when Marne Baca decided to devote full time to the PD Registry. We hope to have the position filled within the next few weeks.

As Evie points out in her piece, fund raising is the key to our ability to continue to serve the PD community and your support of our effort is very much appreciated.

Dick Dunn, President

Executive Director's Report

Happy Summer to all,

Great news to report – we held our 7th Annual Magic of Hope Auction Dinner on May 9th and we raised \$106,000. Thank you all who attended and to those who volunteered at the Event. This year we held the Auction Dinner at The Seattle Renaissance Hotel and we had 300 guests.

Our thanks to our wonderful sponsors:

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The funds raised will be used to continue our Taxi Voucher Program , produce and distribute our DVD, Managing Parkinson's: Straight Talk and Honest Hope, support Dance programs, Yoga and Tai Chi programs, Support Groups, and Educational Programs throughout Washington State. Please contact me if you have programs that you would like to see funded by our Chapter.

Even though we raised all this great money in these strange economical times, please continue to support us by putting a few pennies in your donation envelope.

Enjoy the summer ~ Evie

How to Keep Your Job When You Become Ill

By Monica Steinisch (with thanks to National Young Onset Center for allowing us to reprint)

Many employees would say that, even under the best of circumstances, showing up on time every day and giving 110% to a job can be a challenge. For employees living with chronic illnesses such as Parkinson's disease, MS, or cancer, the average workday is made even more difficult by the demands of managing their condition.

According to the Partnership for Solutions, an initiative to improve the quality of life for those who live with chronic illness, 41% of working-age adults (20 to 65 years) have at least one chronic condition (a medical problem that lasts a year or longer, limits what a person can do, and requires ongoing care). For employees who need—or want—to work, the inevitable question is: How can I hang on to my job?

The law is on your side

First, the federal Americans with Disabilities Act (ADA) requires employers with 15 or more employees to make a “reasonable accommodation” for a disabled worker as long as it does not present an “undue hardship” to the company and the employee can perform the job's essential functions. Reasonable accommodation can cover everything from scheduling more frequent breaks during the day to arranging for work to be done at home.

Under the Family and Medical Leave Act (FMLA), companies with 50 or more workers must provide eligible employees up to 12 weeks of unpaid leave during any 12-month period to deal with the birth or adoption of a child, their own illness, or that of a family member (child, spouse, or parents) without fear of losing their job or medical insurance.

Should you reveal your illness?

To tell or not to tell: On the one hand, you may fear that disclosing a chronic illness will be bad for your career, assuming that your employer will favor healthy workers over ill ones. You also may be concerned that co-workers and supervisors will, accurately or not, perceive you as less able to do your job well, or may pity you. On the other hand, by not disclosing your illness you lose out on any protection, accommodation, and time off provided under the ADA and FMLA. And co-workers left in the dark about your condition may resent being asked to pick up extra work without understanding the reason.

According to Rebecca Hastings, manager of the Society for Human Resource Management information

center, whether or not employees should disclose “will really depend upon their work environment.” Some people who work for companies that encourage close employee relationships feel very comfortable being open about their situation, others feel they need to really watch what they say and do.”

Rosalind Joffe, who as founder of Boston-based Clcoach.com coaches people with chronic illnesses on how to survive and thrive in the workplace, encourages chronically ill workers to “come out of the closet.” Joffe, who herself has lived and worked with chronic illness for 25 years, advises being “as public as you need to be and as private as you want to be.”

If you do decide to tell, experts recommend approaching the conversation with your boss with as much professionalism as you would bring to any work-related discussion. Some other suggestions for making things work include:

- Waiting until you know what kind of accommodation to request (time off, more frequent breaks, permission to work at home, a more ergonomic work station, and so forth) so you can talk specifics.
- Presenting solutions that show your employer you have put serious thought into maintaining the quality of your work and minimizing workplace disruptions.
- Reassuring your supervisor by explaining how you've successfully managed your condition in the past and what you're doing now to keep symptoms under control.
- Always having work with you so are able to be productive even when you can't make it to the office.
- Recognizing supervisors and co-workers when they help and support you.

There was a time when the diagnosis of a chronic illness would mean an end to full-time employment. Thanks to improved medicines and treatments as well as supportive laws and a more enlightened attitude, it's very possible for employees with long-term ailments to adapt and succeed in the workplace. Examine your situation and, if your goal is to keep your job, create a plan that will allow you to do just that.

As Joffe points out in her article, you may not be able to control the course of your illness, but you can control the direction you take and the choices you make regarding that illness in the workplace.

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Continued from page 1. . .

Sexuality, Intimacy and Parkinson's Disease

conversation. Clarifying some of these issues in your own mind may be a helpful first step in getting the conversation between you started.

Once you've begun this internal clarification process, start talking with your partner. Communication is critical! This cannot be overstated. One of the most essential ingredients is listening. Learn how to listen actively and effectively- there's a clear distinction between listening and waiting to talk. Avoid "mind reading" or assuming what your partner means before they've fully expressed themselves. Don't be afraid to check in and make sure you understand them fully before you respond. Learn or rediscover what makes you and your partner feel heard and validated when you are talking. Talk frankly and openly about sexual and intimacy needs. Be clear about what you want, what you need, and what will suffice if you can't have those exact things. It may also be beneficial to identify and then relax your expectations on time limits for communication. Try writing or typing to each other if verbal communication is difficult or laborious and motor changes don't rule this out as a means of communication. It may be helpful to schedule a time to talk about this when energy and mental acuity is at it's highest; at the very least, avoid those times where one partner is overly tired or stressed. Couples or family counseling may be helpful to learn effective communication and listening skills, as well as effective ways to negotiate and compromise. Should you pursue this option, look for a counselor who is well-versed in communication training and neurological disease or behavioral medicine.

Part of your discussions should include what defines intimacy. Many people think of intimacy and sex as the same thing, but there are important ways that couples can experience intimacy without intercourse. Find other ways to be close to one another that deemphasize sexual

intercourse. Talking openly and honestly about what matters and even talking about your fears and concerns can be intimate. Demonstrate love, respect, warmth and togetherness in non-sexual ways, such as holding hands or each other. Kissing and caressing are often where couples begin- revisit this with a newfound curiosity and sense of openness. If sexual intercourse is possible, experiment with different routines (e.g., switch lovemaking to the morning, trying different positions, etc.). As difficult as it may be, the desire to break out of the old routines and adapting to your challenges are the most important ingredients for redefining and rediscovering intimacy.

After you've begun the conversation with each other, it's time to talk to your doctor about treatments, effects of medications, and possible referrals to specialists or counselors, if needed. Treatments for men have received much attention and include oral medications, injections, pumps, vacuum devices, or prostheses. For women, there are oral estrogens, creams, lubricants and devices to provide added stimulation. Keep in mind that not all interventions will work for every individual, every relationship, or every situation. Again, perhaps the most critical intervention is to maintain your curiosity and willingness to keep looking for answers, as well as your ability to keep talking with each other.

In addition to the steps above, it will be critical for you and your partner to keep working toward solutions, repeating the same conversations and experiments as necessary. Acceptance of where you are and "what is" will be important, as will be the need to shift your focus from "what you can no longer do" to "what you can still do." This is no easy task given all of the demands of caregiving and the toll taken by PD. However, remember that you will not find the time for intimacy, you will have to make it!

HOPE.
Parkinson's Disease
 ~ **SAVE THE DATE!** ~

HOPE CONFERENCE
NOVEMBER 7, 2009
 SEATTLE HILTON CONVENTION CENTER
 MORE INFORMATION TO FOLLOW

Washington State Chapter American Parkinson Disease Association Taxi Voucher Program

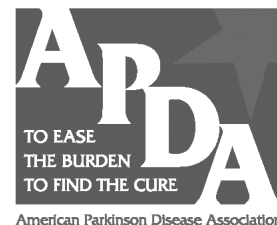
The Washington State Chapter of the APDA is delighted to tell you about our

TAXI VOUCHER PROGRAM.

This program is for those who are unable to drive due to Parkinson's disease or the Parkinson's medications they are taking.

We will provide each client with \$300's worth of Taxi Vouchers for 1 year and all we ask for is a letter from their physician stating that they are no longer able to drive due to Parkinson's Disease. Then forward the letter with your name and address to the address below and we will send the vouchers.

This program has proved to be the most successful program our Chapter has initiated and has given back independence to so many who were unable to get out of their homes to go to their doctors appointments or just to get a cup of coffee.



Washington State Chapter APDA
Attention: Evie Davis
PO Box 75169, Seattle WA 98175
Phone: 425-443-8269
Fax: 866-499-2925
Email: evedavis@gmail.com
Web: www.parkinsons.org

“Managing Parkinson’s: Straight Talk and Honest Hope,”
the DVD produced by the Washington Chapter of the APDA is now available. Topics include medical management, support, care giving, nutrition and diet, exercise, speech therapy, and young onset PD.

Please contact evedavis@gmail.com or (425) 443-8269 to order your free copy.



Thank you for your Greatly Appreciated Donations!

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Washington State Parkinson Support Groups

APDA serves as a clearinghouse for PD Support Groups. If you know of one not listed, listed in error or would like to see one created. . .please tell the Information and Referral Center via contacts on page 2. For Support Groups in Oregon, Alaska and Hawaii, also contact the I&R Center. Before visiting a support group, please contact the group leader to confirm schedule and location.

Idaho

Coeur D'Alene

Lake City Senior Center
Contact: Karen Goodson 208.689.3109
1st Friday of the month 1:00PM

Washington

Anacortes

Island Hospital
contact: Jerry Ramsey 360.293.2185
3rd Thursday of the month 1:00PM

Auburn

Wesley Homes
Contact: Geri Montoya 253.876.6014
1st Friday of the month 10:00AM

Bainbridge

PD Young at H.E.A.R.T. Group
Contact: Steve Bohannon 206.842.0226
sbohann@msn.com
1st Monday of the month 1:00PM

*Bellevue

Young Onset ~ Bellevue Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st Wed. of the month 7:00PM

Bellingham

Parkway Chateau
Contact: Debra Ivanovich 360.724.3382
2nd Monday of the month 2:00PM

*Bothell

North Shore Senior Center
Contact: Susy Favaro 425.486.4564
suzyf@seniorservices.org
2nd Tues. of the month 10:00AM

Bremerton

Harrison Rehabilitation Services
Canterbury Manor
Contact: David Hull 360.895.6220
1st Tues. of the month 1:30PM

Chehalis

Dayspring Baptist Church
Contact: Gwen Moor 360.858.1206
happygp@juno.com

Des Moines

Wesley Homes
Contact: Rita Lambert 206.870.1302
rlambert@wesleyhomes.org
3rd Wednesday of the month 10:00AM

Edmonds

South County Senior Center
Contact: Kathy McNutly 425.774.5555
njbeeler@comcast.net
2nd Wed. of the month 1:00PM

Everett

Rainer Room, Colby Campus,
Providence General Hospital
Contact: Karen Painter 425.327.9401
KPainter62@aol.com
4th Sat. of the month 2:00PM

Gig Harbor

Rosedale Fire Station
Contact: Doug Manuel 253.858.8741
2nd Wednesday 2:00 PM

*Issaquah

Our Savior Lutheran Church
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Monday of the month 1:30PM

Langley

Contact: Carolyn Hansen
360.279.1785
2nd Tuesday of the month 10:00AM
Bay View Senior Center

Longview

Canterbury Inn, 3rd and Hudson
Contact: Barbara Sudar 360.423.7012
bnbsudar@msn.com
3rd Wed. of the month 1:30PM

Kirkland Caregiver Support Group

Tan 138 at Evergreen Hospital
4th Monday of the month 12:30-2PM

Mercer Island

Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st & 3rd Tues. of the month 2:00PM

*Mercer Island

PD Partners -- Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Thurs. of the month 1:30PM

*Mercer Island

Adult Children of Parents with PD --
Community Center at Mercer View
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
3rd Mon. of the month 7:00PM

North Seattle/Shoreline

Shoreline Senior Center
Contact: Scott Tieson 206.268.6761
scottth@seniorservices.org
4th Tues. of the month 11:15AM

*Oak Harbor

North Whidbey Fire Station
Contact: Carolyn Hansen 360.279.1785
1st Friday of the month 1:00PM

Olympia

Evergreen Rehab
Contact: Karen Williams (360) 491-9700
3rd Tuesday of the month @ 11:00 am

Port Angeles/Sequim

Port Angeles Senior Center
Contact: Jan Yates 360.457.9746
4th Wednesday of the month 10:30AM

Port Townsend

Jefferson Healthcare/Telehealth
Contact: Mark Cherniak 360.385.2200
mcherniak@jgc.org
3rd Mon. of the month 2:00PM

Puyallup

United Methodist Church
Contact: Shannon Tait 253.697.8533
shannon.tait@goodsamhealth.org
3rd Thurs. of the month 1:30PM

Puyallup

Caregivers Support Group (Not Only PD)
Good Sam Community Services
Contact: Kathy McCormick 253.697.8400
2nd Monday of the month 1:30PM

Renton

Merrill Gardens at Renton Centre
Contact: Barbara Shull 425.235.6400
3rd Wed. of the month 1:30PM

Richland

Neurological Research Center
Contact: Heidi Hill 509.943.8455
hillh@kadlecmed.org
2nd Thurs. of the month 1:30PM

*Seattle

Seattle PD Partners --
Greenwood Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
2nd Tues. of the month 1:00PM

Seattle

Young Onset -- meets in members homes
Contact: Suzanne Cameron 206.286.8149
2nd Tues. of the month 7:00PM

Seattle

Well Spouse -- Greenwood Senior Center
Contact: Carin Mack 206.230.0166
socialwkr@earthlink.net
1st Mon. of the month 4:00PM

Seattle

Swedish Hospital
Contact: Peggy Shortt, ARNP 206.320.2849
2nd Tuesday 1:00 PM - Begins in April

Seattle First Hill

Horizon House
Contact: Carin Mack
206.230.0166
socialwkr@earthlink.net
4th Monday 1:30PM

South Seattle

South Park Community Center
Contact: Nancy Swigger 206.684.7451
nancyinseattle@gmail.com
3rd Thursday @ 9:30 pm

Spokane

St. Lukes Rehab Institute
Contact: 509.473.2490
3rd Mon. of the month 2:00PM

Spokane (Dystonia)

St. Lukes Rehab Institute
Contact: Denise Gibson 509.891.9131
denise@designnden.com
2nd Sat. of the month 1:00PM

Spokane (Women's)

Location changes -- contact group leader
Contact: Julie Willis 509.467.2240
1st Thurs. of the month 1:00PM

Stanwood

Warm Beach Methodist Church
Contact: Tori Kelly 425.422.1067
2nd Monday of the month @ 9:00 am

Tacoma

Tacoma Lutheran Home
Contact: Sharon Jung 253.284.4488
3rd Friday of the month 11:30AM

Vancouver

Legacy Salmon Creek
Contact: Lynda Forbes-Cramer
360.546.1763
lfcramer@comcast.net
3rd Sat. of the month 1:00PM

Vancouver

Locations and time varies
Contact: Jeanne 360.892.0686

Vashon island

Contact: Kate Lanigan 206.463.3140

Walla Walla

Congregational Church
Contact: Darlene Lambert 509.382.4012
4th Sat. of the month 6:00PM

Washington Peninsula

Ocean park Lutheran church
Contact: Patti Pellerin 360.665.3284
4th Fri. of the month 1:30PM

Wenatchee

Wellness Center 509.884.6833
Contact: LaVerna Armintrout 509.662.6069
Call for details

West Seattle

Admiral Congregational UCC
Contact: Katie Stokely 206.933.5931
3rd Thurs. of the month 1:30PM

West Seattle

Providence Mount St. Vincent
Contact: Suzanna Eller 206.938.8298
Call for details

Yakima

Park Meadows
Contact: Jaci Rice 509.248.9963
2nd Thurs. of the month 2:00PM

***Denotes APDA Affiliation**

APDA Event Calendar

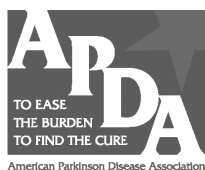
Date	Event
July 21	Educational Patient Program, Yakima, Speakers include Dr. Ali Sami, Dr. Laurie Mischley and Karen Ward PT <i>Registration Required. Please contact Evie Davis at 425-443-8269 or evedavis@gmail.com</i>
July 22	Longview Support Group Meeting with Dr. Neville
August 15	Wenatchee Support Group Meeting with Dr. Ali Sami
August 18	Educational Patient Program, Kirkland Speakers include Dr. Pinky Agarawal, Dr. Jeff Shaw, Ann Zylstra PT <i>Registration Required. Please contact Evie Davis at 425-443-8269 or evedavis@gmail.com</i>

*Thank you, Teva Neuroscience, for sponsoring these programs.
Lunch will be served and there is no charge for these programs.*

June 22	Occupational Therapy and Parkinsons Disease Ron Porter, OTR, Virginia Mason
July 27	Support Group Meeting, Horizon House, 900 University St., Seattle, WA 98101 206-624-3700, There is minimal paid parking in the garage. Group facilitated by Carin Mack, MSW, 206-230-0166, socialwkr@earthlink.net Private Counseling available

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