

Finding Your Community: Women with Parkinson's

Jennifer Parkinson, *StrongHer Women Fighting Parkinson's!*

Newbury Park, CA



Sex and Gender Differences in Parkinson's

- **Women are less likely to develop Parkinson's** (G. Wooten, L. Currie, et al. (2004))
- **Small changes in medication schedule or dosage are more likely to cause dyskinesia in women** (L. Shulman (2007))
- **Women are less likely to seek specialized care for their Parkinson's** (A. Willis, M. Schootman, et al. (2011))
- **Women are less likely than men to undergo deep brain stimulation** (A. Willis, M. Schootman, et al. (2014))



Goals for this session

- Identify the aspects of women's social roles that may become challenging with Parkinson's and strategies to adapt
- Discuss ways to improve communication with your medical team
- Explore the importance of a community of women to support you through your Parkinson's

Women's Social Roles

The behaviors and attitudes that comprise how women interact with others and society

Women as Care Providers



Women's Social Roles in Society



Shifting from Care Provider to Care Recipient

When & how to ask for help with your Parkinson's

In the Family



With Your Partner or Spouse

- Conversations with your partner are also key so that...
 - They can support your family's needs
 - You feel like you can ask for help
 - They know how they can support you
 - The dialogue remains open for other important conversation:
 - Your partner or spouse's needs as your care partner
 - Intimacy and Sex
 - Etc.

In the Workplace



Inner Strength

- It's okay to not be okay
- **You deserve help!**
- Find victories in being an advocate for your care in this journey
 - Be it with your family, in your exercise routines, your nutrition or with your medical team

Improving Communication with Your Medical Team

Finding the right doctor for YOU and making the most of your appointments

Finding the Right Doctor for You

- Someone who listens, is sympathetic action-oriented and that you feel asking questions of
- Plan to 'shop around'
 - [MDS Search tool](#) for potential doctors in your area
 - Ask for recommendations from people you know
- Applies for more than just your Movement Disorder Specialist, same for your General Practitioner and other providers



Maximizing your Appointments

- Sign medical releases so that all of your doctors are on the same page with your care
- Have your care partner, friend or someone with you and record the appointment so you can refer back
- Use [worksheets](#) to track symptoms, manage care and encourage discussion
 - Send worksheets or appointment agenda in advance
 - Useful for “sensitive subjects” like incontinence or intimacy
 - Ensures you don’t miss something you wanted to discuss

Your Care Team Includes Your Community

Finding a community of women to support you through your Parkinson's

Your Family and Medical Team Play a Critical Role in Your Parkinson's Care

- It's important for them to have an outlet, just as it is for you
- There are benefits to connecting with other people with Parkinson's
 - Moral support
 - Information such as doctor recommendations and tips
 - Friendship



DAVIS PHINNEY
Foundation For Parkinson's

every victory counts.

Workshop

Small group discussion to sample a women's support group

Discussion Starters

- Do you feel your family dynamic has changed since diagnosis and if so, how?
- What is the hardest subject for you to talk about when it comes to your Parkinson's?
- What is the best piece of advice you have received regarding Parkinson's?
- How do you define 'self-care' and how do you make time for it in your day?
- What brings you joy?
- Do you feel there is an area lacking in your Parkinson's care or support team? If so, please describe.
- Who has been your greatest supporter and what does their support mean to you?
- How do you maintain "work/life balance"?
- Do you have tips for simplifying your beauty routine?
- Is there an exercise program in the area you enjoy and if so, why?

Action Steps

If you found this discussion helpful or want to connect with more women in your area with Parkinson's, join or start a support group!

Action Steps

- Sign-up slips being passed around for those interested in starting or joining a local women's support group
- Pick up a [Women and PD Fact Sheet](#) to take home with you
- Read the [Davis Phinney Foundation's blog](#) for more articles relating to Women with Parkinson's

Thank you!

Questions?

Don't forget to drop off your **blue survey up front on your way out!**

For more resources on how to live well and find all presentations from the day, visit our website at www.dpf.org