

Experiences of Women Living with PD

Female Health and Home Life

[BLOCK 1] Introduction

Thank you for your interest. This survey focuses on the experiences of women living with Parkinson's disease.

We anticipate that this survey will take on average 20 – 30 minutes, however your answers will be saved so you can return and pick up where you left off.

Multiple choice, single answer, required

1. What sex were you assigned at birth, on your original birth certificate?
 - a. Male
 - b. Female
 - c. Prefer not to answer

Multiple choice, single answer, required

2. What is your current gender identity?
 - a. Male
 - b. Female
 - c. Transgender male
 - d. Transgender female
 - e. Other (gender non-conforming, genderqueer, non-binary, etc.)
 - f. Not sure
 - g. prefer not to answer

Skip Logic: If (a. Male) is selected, skip to End of Survey thank you 1.

Skip Logic: If (d. Transgender female) (d. Other), (e. Not Sure) or (f. Prefer not to answer) is selected for "What is your current gender identity?" skip to End of Survey thank you 2

3. When did you transition?
 - a. I transitioned from female to male-identifying while premenopausal (menopause is when you stop having periods for 12 consecutive months, experience a drop in estrogen levels, and marks the end of reproductive years) .
 - b. I transitioned from female to male-identifying while experiencing perimenopause (perimenopause is the transitional period before menopause that can last for years, during which you might experience menopause-like symptoms).
 - c. I transitioned from female to male-identifying while postmenopausal (post-menopausal refers to the period of time after menopause has occurred)
 - d. Prefer not to answer

Display Logic: If (c. Transgender male), is selected for "What is your current gender identity?"

Multiple choice, single answer, required

4. Have you been diagnosed with Parkinson's disease?
 - a. Yes, I have been diagnosed with Parkinson's disease
 - b. No, I have not been diagnosed with Parkinson's disease

Skip Logic: If (b. No, I have not been diagnosed with Parkinson's disease) is selected, skip to End of Survey.

Multiple choice, multiple answer, required

5. My Parkinson's was diagnosed:

Please select all that apply.

- a. While I was still having periods
- b. During pregnancy
- c. Up to a year after pregnancy
- d. While I was going through perimenopause (perimenopause is the transitional period before menopause that can last for years, during which you might experience menopause-like symptoms).
- e. After surgical or induced menopause (menopause is when you stop having periods for 12 consecutive months, experience a drop in estrogen levels, and marks the end of reproductive years).
- f. After natural menopause
- g. Not sure
- h. Prefer not to answer

Multiple choice, single answer, required

6. What life phase currently applies to you?
- a. I am still menstruating (either a natural regular menstrual cycle while on birth control devices or medications)
 - b. I am on birth control but do not experience periods
 - c. I have had a hysterectomy (a hysterectomy is a surgical procedure to remove the uterus) without removing ovaries and have not gone through menopause
 - d. I have had a hysterectomy without removing ovaries and have gone through menopause
 - e. I am experiencing induced chemical menopause (induced chemical menopause is the stoppage of menstrual periods due to chemotherapy or radiation damage to the ovaries, or from the use of other medications such as Lupron)
 - f. I am going through perimenopause / menopause
 - g. I am post-menopausal (post-menopausal refers to the period of time after menopause has occurred)
 - h. Not sure
 - i. Prefer not to answer

Female Health History

Multiple choice, single answer, required

7. Were/are you offered regular Pap smear tests by one or more of your healthcare providers?
- a. Yes
 - b. No, I have never been offered a PAP smear
 - c. No, I have not been offered a PAP smear since my PD diagnosis
 - d. Not sure
 - e. Prefer not to answer

Multiple choice, single answer, required

8. Were/are you offered regular mammograms by one or more of your healthcare providers?
- a. Yes
 - b. No
 - c. Not sure
 - d. Not of age for screening yet
 - e. Prefer not to answer

Multiple choice, single answer, required

9. Did you have, or have you been offered BMD (bone mineral density) measurement (if applicable)?
- a. Yes, I requested it
 - b. Yes, my healthcare provider suggested it
 - c. No, my age doesn't qualify for this

- d. No
- e. Not sure
- f. Prefer not to answer

Multiple choice, single answer, required

10. Have you been diagnosed with thinning of the bones (osteopenia or osteoporosis)?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

10. Did you have, or have you been offered a vitamin B12 test?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

11. Did you have, or have you been offered a vitamin D test?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

11. Have you ever been offered blood tests to assess your hormone levels?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, single answer, required

12. Does/did your Parkinson's healthcare team ask you about your menstrual cycle and whether it affects your Parkinson's symptoms?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, multiple answer, required

13. Did/has your Parkinson's healthcare team suggested any management for your menstrual cycle or menopausal status? Please select all that apply.
- a. Changing or increasing/decreasing Parkinson's medication
 - b. Birth control devices or medication
 - c. Hormone Replacement Therapy (HRT)
 - d. Other
 - e. Not sure
 - f. No

- g. Prefer not to answer

Multiple choice, single answer, required

14. Were/are you hesitant to raise questions to your Parkinson's healthcare team around hormones and menstruation/menopause?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, multiple answer, required

15. Please select all reasons you were/are hesitant to raise questions around hormones and menstruation/menopause to your Parkinson's healthcare team:

- a. I did not realize hormones may affect my PD
- b. I am embarrassed to bring up the subject of my hormones
- c. I feel embarrassed talking about hormones/menstruation with male healthcare providers
- d. They do not provide me an opportunity to ask the question
- e. I don't feel they are interested or knowledgeable
- f. I feel that they dismiss the issues with my hormones
- g. There isn't time to discuss given other issues
- h. Other
- i. Not sure
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were/are you hesitant to raise questions to your healthcare provider around hormones and menstruation/menopause?"

Multiple choice, single answer, required

16. Have you ever experienced a change in odor from your vagina in between your periods?

- a. Yes
- b. No
- c. I have no/limited sense of smell
- d. Not sure
- e. Prefer not to answer

Multiple choice, single answer, required

17. When did you first notice a change in odor from your vagina in between your periods?

- a. Before diagnosis of Parkinson's
- b. After diagnosis of Parkinson's
- c. Other
- d. Not sure
- e. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Have you ever experienced a change in odor from your vagina in between your periods?"

Multiple choice, single answer, required

18. Have you ever experienced a creamy discharge from your vagina in between your periods?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

19. Did you noticed more tenderness in the vaginal area when the discharge is present (e.g., when wiping yourself after urinating or during sexual intercourse?)

- e. Yes
- a. No
- b. Not sure
- c. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you ever experienced a creamy discharge from your vagina in between your periods?”

Text box, single answer, required

20. If you visited a physician for treatment of this discharge, what was the diagnosis?

- a. Infection
- a. Side effect of medication
- b. Other
- c. Unknown/undiagnosed
- d. I did not visit a physician
- e. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you noticed more tenderness in the vaginal area when the discharge is present (e.g., when wiping yourself after urinating or during sexual intercourse?”

Multiple choice, single answer, required

21. Was there any medication prescribed after receiving this diagnosis?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a. Infection), (b. Side effect of medication), or (c. Other) is selected for “If you visited a physician for treatment of this discharge what was the diagnosis?”

Multiple choice, single answer, required

22. Did the medication alter the discharge?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Was there any medication prescribed after receiving this diagnosis?”

23. Was the discharge still present after treatment?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Was there any medication prescribed after receiving this diagnosis?”

Home Life

Multiple choice, multiple answer, required

23. What is your work status? Please select all that apply.

- a. Employed part-time outside the home
- b. Employed full-time outside the home
- c. Full-time parent
- d. Not employed
- e. Self-employed part-time
- f. Self-employed full-time
- g. Voluntary unpaid work full-time
- h. Voluntary unpaid work part-time
- i. Short term disability
- j. Long term disability/ill health retired
- k. Early retirement
- l. Retired
- m. Other
- n. Prefer not to answer

Multiple choice, single answer, required

24. What was your work status before you got diagnosed with Parkinson's?

- a. Part-time outside the home
- b. Full-time outside the home
- c. Full-time parent
- d. Not employed
- e. Self-employed part-time
- f. Self-employed full-time
- g. Voluntary work full-time
- h. Voluntary work part-time
- i. Short term disability
- j. Long term disability/ill health retired
- k. Early retirement
- l. Retired
- m. Other
- n. Prefer not to answer

Multiple choice, single answer, required

25. Did you reduce your workload, stop working, or change jobs as a result of your Parkinson's disease diagnosis?

- a. Yes, immediately
- b. Not immediately but within 5 years
- c. Not immediately but after 5 years
- d. No
- e. Prefer not to answer

Multiple choice, multiple answer, required

26. What was the reason to reduce workload, stop working, or change jobs? Please select all that apply.

- a. Own choice/my preference
- b. Due to PD motor symptoms
- c. Due to PD non-motor symptoms
- d. Due to mental or cognitive issues

- e. Due to non-PD associated physical symptoms
- f. Due to workplace safety issues / restrictions
- g. Pressured/forced by my manager/boss/employer
- h. Pressured by family or others
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes, immediately), (b. Not immediately but within 5 years), or (c. Not immediately but after 5 years) is selected for “Did you reduce your workload, stop working, or change jobs as a result of your Parkinson’s disease diagnosis?”

27. Which category **best** describes your longest held occupation? *Please select one*

- a. Management
- b. Business and Financial Operations
- c. Computer and Mathematical
- d. Architecture and Engineering
- e. Life, Physical, and Social Science
- f. Community and Social Service
- g. Legal
- h. Educational Instruction and Library
- i. Arts, Design, Entertainment, Sports, and Media
- j. Healthcare Practitioners and Technical
- k. Healthcare Support
- l. Protective Service
- m. Food Preparation and Serving Related
- n. Building and Grounds Cleaning and Maintenance Occupations
- o. Personal Care and Service Occupations
- p. Sales and Related Occupations
- q. Office and Administrative Support Occupations
- r. Farming, Fishing, and Forestry Occupations
- s. Construction and Extraction Occupations
- t. Installation, Maintenance, and Repair Occupations
- u. Production Occupations
- v. Transportation and Material Moving Occupations
- w. Military
- x. None of the above
- y. Prefer not to answer

Multiple choice, single answer, required

28. Have you been or are you currently in a relationship (e.g., marriage, domestic partnership etc.)?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

29. Did your Parkinson’s contribute to a change in your relationship?

- a. Yes, in a positive way
- b. Yes, in a negative way
- c. Yes, my relationship ended
- d. No change
- e. Not sure

- f. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you been or are you currently in a relationship (e.g., marriage, domestic partnership etc.)?”

Multiple choice, single answer, required

30. Do you live alone?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

31. Do you live alone by choice?

- a. Yes
- b. No
- c. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you live alone?”

Multiple choice, single answer, required

32. Do you live in an assisted care facility?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

33. What is your contribution to your total household income?

- a. 0% -24%
- b. 25% - 49%
- c. 50% -74%
- d. 75% - 99%
- e. 100%
- f. Prefer not to answer

Multiple choice, single answer, required

34. What is your contribution to cleaning and household chores?

- a. 0% -24%
- b. 25% - 49%
- c. 50% -74%
- d. 75% - 99%
- e. 100%
- f. Prefer not to answer

Multiple choice, single answer, required

35. What is your contribution to cooking and meal planning?

- a. 0% -24%
- b. 25% - 49%
- c. 50% -74%
- d. 75% - 99%
- e. 100%
- f. Prefer not to answer

Multiple choice, single answer, required

36. What is your contribution to financial planning and bill paying?

- a. 0% -24%
- b. 25% - 49%
- c. 50% -74%
- d. 75% - 99%
- e. 100%
- f. Prefer not to answer

Multiple choice, single answer, required

37. Do you have children under the age of 18 living at home with you?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

38. Regardless of whether you have a partner, what do you think is your contribution to overall care of your children?

- a. 0% -24%
- b. 25% - 49%
- c. 50% -74%
- d. 75% - 99%
- e. 100%
- f. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you have children under the age of 18 living at home with you?”

Multiple choice, single answer, required

39. Overall, do you feel that caring for children and your home are primarily your responsibility?

- a. I’m a single parent
- b. Yes
- c. No
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you have children under the age of 18 living at home with you?”

Multiple choice, multiple answer, required

40. Do you have help taking care of your home and / or property?

- a. Yes, paid help
- b. Yes, unpaid help
- c. No
- d. Would like to but cannot afford help
- e. Would like to but cannot find help
- f. Prefer not to answer

Multiple choice, single answer, required

41. Do you have help with your activities of daily living (e.g., walking, feeding, dressing, or grooming) from an outside care provider?

- a. Yes
- b. No
- c. Prefer not to answer

Text box, numerical integer response limited to 0-168, required

42. How many hours per week do you need help with your activities of daily living from an outside care provider (please enter a value from 1-168 hours)? If you are not sure, please make your best guess.

a. **Hours per week:** _____

Display Logic: If (a. Yes) is selected for “Do you have help with your activities of daily living (e.g., walking, feeding, dressing, or grooming) from an outside care provider?”

Multiple choice, single answer, required

43. Do you take care of anyone else outside your home?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

44. Do your family and work responsibilities make it difficult to manage your Parkinson’s symptoms?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

45. Do your family and work responsibilities make it difficult to find time to exercise?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

46. Do your family and work responsibilities make it difficult to practice self-care (e.g., maintaining hygiene or nutrition; engaging in sporting or leisure activities; managing your living conditions or medications)?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

47. Has your Parkinson’s disease diagnosis affected your self-image?

- a. Yes, negatively
- b. Yes, positively
- c. No
- d. Not sure
- e. Prefer not to answer

Multiple choice, multiple answer, required

48. What aspects of your diagnosis negatively affect /affected your self-image? Please select all that apply.

- a. Weight loss
- b. Weight gain
- c. Acne
- d. Dry skin
- e. Oily skin
- f. Hair changes
- g. Speech
- h. Tremor

- i. Rigidity
- j. Dyskinesia
- k. Gait changes
- l. Slowness
- m. Facial masking
- n. Drooling
- o. Urinary urgency/incontinence
- p. Issues with hygiene
- q. Issues with getting dressed
- r. Other
- s. Not sure
- t. Prefer not to answer

Display Logic: If (a. Yes, negatively) is selected for “Has your Parkinson’s disease diagnosis affected your self-image?”

Multiple choice, single answer, required

49. Does your Parkinson’s interfere with your social interactions?
- a. Yes always
 - b. Yes sometimes
 - c. No
 - d. Prefer not to answer

50. To what extent has PD interfered with your social interactions?
- a. Very mildly
 - b. Mildly
 - c. Moderately
 - d. Severely
 - e. Prefer not to answer

Display Logic: If (a. Yes sometimes) or (b. Yes always) is selected for “Does your Parkinson’s interfere with your social interactions?”

Multiple choice, single answer, required

51. Has your level of sexual activity changed with your Parkinson’s diagnosis?
- a. Yes, I am less sexually active
 - b. Yes, I am more sexually active
 - c. No change
 - d. Prefer not to answer

Multiple choice, single answer, required

52. Do you have decreased libido?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes, I am less sexually active) is selected for “Has your level of sexual activity changed with your Parkinson’s diagnosis?”

Multiple choice, single answer, required

53. Do you or have you used an app to track your menstrual cycle?
- a. Yes
 - b. No, I haven’t found one that works for me
 - c. No, I don’t want / need to
 - d. No, I don’t know how to

- e. Not applicable
- f. Prefer not to answer

Display Logic: If (a. I am still menstruating (either a natural regular menstrual cycle while on birth control devices or medications)) is selected for “What life phase currently applies to you?”

Multiple choice, single answer, required

54. Do you think the app provides enough information to inform discussions with your healthcare provider?
- a. Yes
 - b. No
 - c. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you or have you used an app to track your menstrual cycle?”

Multiple choice, single answer, required

55. If there was an app that tracked both Parkinson’s and hormonal fluctuations, would you use it?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you or have you used an app to track your menstrual cycle?”

Multiple choice, single answer, required

56. Have you taken part in research for Parkinson’s other than Fox Insight Surveys?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, multiple answer, required

57. What type of research besides Fox Insight have you taken part in? Please select all that apply.
- a. Genetic
 - b. Medication
 - c. Wearable device
 - d. Lifestyle intervention (for example diet / exercise)
 - e. Mindfulness
 - f. Surgical
 - g. One time survey studies
 - h. Repeat surveys
 - i. Clinical studies following life history of Parkinson’s
 - j. Other
 - k. Not sure
 - l. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Have you taken part in research for Parkinson’s other than Fox Insight Surveys?”

End of Survey thank you 1:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people whose gender identity is female. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey thank you 2:

Thank you for participating in Fox Insight. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey thank you 3:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people who have been diagnosed with Parkinson's disease. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey thank you 4:

Thank you for taking part in this survey. Your answers will help us learn more about your experience living with PD. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**