

Experiences of Women Living with PD - Pre, Peri, and Post Menopause

INTRODUCTION

Thank you so much for taking part in this survey. This is a comprehensive survey designed by women with Parkinson's. The aim of this survey is to try to better understand women's health as it relates to PD, specifically the menstrual cycle.

We anticipate that this survey will take an average of 5 – 10 minutes. However, your answers will be saved so you can return and pick up where you left off. Once again, thank you so much for sharing your vital insights of living with Parkinson's to inform future research.

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

Display Logic: If (a. Male) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- b. Female

Display Logic: If (b. Female) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- c. Transgender male

Display Logic: If (b. Female) is selected for "What sex were you assigned at birth, on your original birth certificate?". Transgender female

Display Logic: If (a. Male) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- d. Other (gender non-conforming, genderqueer, non-binary, etc.)
 - e. Not sure
 - f. Prefer not to answer

Skip Logic: If (a. Male) is selected for "What is your current gender identity?", skip to End of Survey thank you 1.

Skip Logic: If (a. Male) is selected for "What sex were you assigned at birth, on your original birth certificate?" AND (e. Other) is selected for "What is your current gender identity?", or if (d. Transgender female), (f. Not sure) or (g. 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 your 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 and/or have an irregular menstrual cycle)
- c. I transitioned from female to male-identifying while post-menopausal (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 thank you 3.

Multiple choice, multiple answer, required

- 5. My Parkinson’s was diagnosed:
Please choose the best answer.
 - 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 and/or have an irregular menstrual cycle).
 - e. After surgical or medically induced menopause (surgical or medically induced menopause is when menopause is the result of a surgical procedure or a result of medication given to you by your physician)
 - f. After natural menopause (menopause is when you stop having periods for 12 consecutive months, experience a drop in estrogen levels, and marks the end of your reproductive years)
 - g. Not sure
 - h. Prefer not to answer

- 6. Have you had any of the following procedures?
 - a. Surgical removal of uterus (hysterectomy)
 - b. Surgical removal of both ovaries (oophorectomy)
 - c. Surgical removal of one ovary (oophorectomy)
 - d. Surgical removal of uterus and one ovary
 - e. Surgical removal of uterus and both ovaries
 - f. None of the above
 - g. Prefer not to answer

Skip Logic: If (b. Surgical removal of both ovaries (oophorectomy) or (e. Surgical removal of uterus and both ovaries) is selected, skip to post-menopause section: “Your prior answers indicate you are in menopause. We will now ask you questions about your experiences in this life phase.”

Multiple choice, single answer, required

- 7. What life phase **currently** applies to you? Please choose the best answer.

- a. I am pre-menopausal. I am either still menstruating or my periods have temporarily stopped due to a birth control device or medication.
- b. I am going through perimenopause / menopause (perimenopause is the transitional period before or around menopause that can last for years, during which you might experience menopause-like symptoms and/or have an irregular menstrual cycle. Menopause is when you stop having periods for 12 consecutive months, experience a drop in estrogen levels, and marks the end of your reproductive years)
- c. I am post-menopausal (post-menopausal refers to the period of time after menopause has occurred. Menopause is when you stop having periods for 12 consecutive months, experience a drop in estrogen levels, and marks the end of your reproductive years.)
- d. Not sure
- e. Prefer not to answer

Skip Logic: If (a. I am still menstruating (either a natural regular menstrual cycle or blood loss while on birth control devices or medications) is selected, skip to “Have you ever used a birth control device or birth control hormones?”. If (b. I am going through perimenopause / menopause) is selected, skip to “Has your perimenopausal or menopausal status been diagnosed by a healthcare professional?” If (c. I am post-menopausal) is selected, skip to “Approximately what age were you when you became post-menopausal? If you are not sure, please make your best guess.” If (d. Not sure) or (e. Prefer not to answer) is selected, skip to End of Survey thank you 2.

PRE-MENOPAUSE

- 8. Have you ever used a birth control device or birth control hormones?
 - a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Skip Logic: If (b. No) is selected, skip to “Has your menstrual cycle changed since the onset of Parkinson’s symptoms?”

Multiple choice, single answer, required

- 9. Do you currently have a natural menstrual cycle, or do you use birth control devices or hormones (estrogen/progestin) **that regulate your cycle?**
 - a. Natural menstrual cycle *not* regulated by hormonal birth control
 - b. Hormone-regulated menstrual cycle (hormonal birth control)
 - c. Other
 - d. Not sure
 - e. Prefer not to answer

Multiple choice, multiple answer, required

- 10. What types of birth control did you use **before** your diagnosis of Parkinson’s? Please select all that apply.
 - a. Birth Control Pill/Oral contraceptive pill
 - b. Birth Control Ring
 - c. Arm implant

- d. Hormonal intrauterine device (IUD)
- e. Copper IUD
- f. Tubal ligation
- g. Birth Control Patch
- h. Other (Condoms, etc.)
- i. None
- j. Not sure
- k. Prefer not to answer

Multiple choice, multiple answer, required

11. What types of birth control have you used **since** your diagnosis of Parkinson's? Please select all that apply.
- a. Birth Control Pill/Oral contraceptive pill
 - b. Birth Control Ring
 - c. Arm implant
 - d. Hormonal intrauterine device (IUD)
 - e. Copper IUD
 - f. Tubal ligation
 - g. Birth Control Patch
 - h. Other (Condoms, etc.)
 - i. None
 - j. Not sure
 - k. Prefer not to answer

Multiple choice, single answer, required

12. What type of birth control do you **currently** use? Please choose the best answer.
- a. Birth Control Pill/Oral contraceptive pill
 - b. Birth Control Ring
 - c. Arm implant
 - d. Hormonal IUD
 - e. Copper IUD
 - f. Tubal ligation
 - g. Birth Control Patch
 - h. Other (Condoms, etc.)
 - i. None
 - j. Not sure
 - k. Prefer not to answer

13. In what way do you use your oral contraceptive pill?
- a. I take pills (and menstruate once every 28 days)
 - b. I take the pill continuously (to avoid menstruation) and have a stop week occasionally
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Birth Control Pill/Oral contraceptive pill) is selected for "What type of birth control do you currently use?"

14. Did you start birth control because you were diagnosed with Parkinson's disease?
- a. Yes

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

Display Logic: If (i. None) is NOT selected for “What types of birth control have you used **since** your diagnosis of Parkinson’s? Please select all that apply”

15. Did you change your birth control because you were diagnosed with Parkinson’s disease?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

16. How many times have you changed your birth control since being diagnosed with PD? Please choose the best answer.
- a. Once
 - b. Twice
 - c. Three or more
 - d. Not sure
 - e. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you change your birth control because you were diagnosed with Parkinson’s disease?”

Multiple choice, multiple answer, required

17. If you started birth control or changed the type of birth control used after your Parkinson’s diagnosis, what was the reason? Please select the best choices.
- a. To prevent pregnancy
 - b. On my doctor’s recommendation
 - c. To regulate my menstrual cycle and menstrual symptoms
 - d. To regulate my Parkinson’s symptoms which change around my period
 - e. To regulate my mood
 - f. To maintain the effectiveness of my Parkinson’s medications
 - g. Other
 - h. Not applicable
 - i. Not sure
 - j. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you start birth control because you were diagnosed with Parkinson’s disease?” OR (a. Yes) is selected for “Did you change your birth control because you were diagnosed with Parkinson’s disease?”

18. If you started or changed your birth control due to your PD diagnosis, who prompted the change?
- a. Me
 - b. My doctor or healthcare team
 - c. Both
 - d. Other
 - e. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you start birth control because you were diagnosed with Parkinson’s disease?” OR (a. Yes) is selected for “Did you change your birth control because you were diagnosed with Parkinson’s disease?”

Multiple choice, multiple answer, required

19. If you started or changed the type of birth control used after your Parkinson’s diagnosis, what did you change to? Please select all the apply.
- a. Birth Control Pill/Oral contraceptive pill
 - b. Birth Control Ring
 - c. Arm implant
 - d. Hormonal IUD
 - e. Copper IUD
 - f. Tubal ligation
 - g. Birth Control Patch
 - h. Other (Condoms, etc.)
 - i. None
 - j. Not sure
 - k. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Did you start birth control because you were diagnosed with Parkinson’s disease?” OR (a. Yes) is selected for “Did you change your birth control because you were diagnosed with Parkinson’s disease?”

20. Did you notice a change in your Parkinson’s symptoms when using a hormonal birth control device or pills?
- a. Yes
 - b. No
 - c. Not applicable
 - d. Not sure
 - e. Prefer not to answer

Display Logic: If (a. Birth Control Pill/Oral contraceptive pill), (b. Birth Control Ring), (c. Arm implant), or (d. Hormonal IUD) is selected for “If you started or changed the type of birth control used after your Parkinson’s diagnosis, what did you change to?”

Multiple choice, single answer, required

21. Did you notice any improvement in your Parkinson’s symptoms (motor and non-motor) when using a hormonal birth control device or pills?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Birth Control Pill/Oral contraceptive pill), (b. Birth Control Ring), (c. Arm implant), or (d. Hormonal IUD) is selected for “If you started or changed the type of birth control used after your Parkinson’s diagnosis, what did you change to?”

Multiple choice, single answer, required

22. Has your menstrual cycle changed since the onset of Parkinson's symptoms?

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

Multiple choice, multiple answers, required

23. How has your menstrual cycle changed since the onset of Parkinson's symptoms? Please select all that apply.

- a. Heavier blood flow
- b. Lighter blood flow
- c. Longer periods
- d. Shorter periods
- e. Occurred more frequently
- f. Became less frequent
- g. Became unpredictable
- h. Less Cramping
- i. More Cramping
- j. Other
- k. Not sure
- l. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Has your menstrual cycle changed since the onset of Parkinson's symptoms?"

Multiple choice, multiple answer, required

24. Have you noticed that your Parkinson's symptoms change in relationship to your menstrual cycle?

- a. Yes, with consistent or predictable change
- b. Yes, with inconsistent or unpredictable change
- c. No
- d. Not sure
- e. Prefer not to answer

Multiple choice, multiple answer, required

25. During what phase of your menstrual cycle do your Parkinson's symptoms change? Please select all that apply

- a. The week before my period
- b. A couple of days before my period
- c. The first couple of days of my period

- d. The last days of my period
- e. A couple of days after my period
- f. The week after my period
- g. Two weeks before my next period
- h. Other
- i. Not sure
- j. Prefer not to answer

Display Logic: If (a. Yes, with consistent or predictable change) or (b. Yes, with inconsistent or unpredictable change) is selected for “Have you noticed that your Parkinson’s symptoms change in relationship to your menstrual cycle?”

Multiple choice, single answer, required

26. Do you notice that your Parkinson’s symptoms change around the time of ovulation?
Ovulation is when an egg is released from one of your ovaries and usually occurs around 10-16 days before your period starts.
- a. Yes
 - b. Sometimes
 - c. No
 - d. Not sure
 - e. Prefer not to answer

Display Logic: If (a. Yes, with consistent or predictable change) or (b. Yes, with inconsistent and unpredictable change) is selected for “Have you noticed that your Parkinson’s symptoms change in relationship to your menstrual cycle?”

Multiple choice, multiple answer, required

27. Which Parkinson’s **movement** symptoms **change** during your period?
 Please select all that apply.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time – period during which PD medication(s) do not work as well
- j. Dyskinesia – uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. Restless legs – irresistible urge to move your legs
- l. Cramping and dystonia – involuntary muscle contractions, sometimes causing slow repetitive or twisting movements
- m. None of the above

Display Logic: If (a. Yes, with consistent or predictable change) or (b. Yes, with inconsistent and unpredictable change) is selected for “Have you noticed that your Parkinson’s symptoms change in relationship to your menstrual cycle?”

28. In the prior question, you selected the following Parkinson's movement symptoms because you notice a change in those symptoms during your period. Please select how you feel these symptoms change during your period.

Display Logic: If (m. None of the above) is NOT selected for "Which Parkinson's movement symptoms change during your period?"

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer
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Display Logic: If any symptom is selected for any item in "Which Parkinson's *movement* symptoms change during your period?", corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

29. Which Parkinson's **thinking, feeling, and sleep** symptoms **change** during your period?

Please select all that apply.

- Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- Trouble staying awake during the daytime
- Acting out your dreams while asleep – punching, flailing your arms in the air, making running movements, etc.
- Trouble thinking clearly, remembering things, and being attentive
- Memory loss- trouble remembering things
- Confusion – not knowing where you are, the date/time, who familiar people are
- Hallucinations – hearing, seeing, feeling, tasting, or smelling something that is not really there
- Anxiety – feeling nervous, worried, or tense more than usual and/or panic attacks
- Depression – periods of sadness, hopelessness, emptiness, or loss of enjoyment
- Fatigue – physical and mental state of having extremely low energy
- Apathy – decreased motivation, initiative, or spontaneity
- Irritability and frustration
- Paranoia or suspicion – having false, often paranoid, beliefs (delusions), such as that a spouse is being unfaithful, or money is being stolen
- Obsessive and unreasonable thoughts and fears
- Inability to control impulsive urges
- None of the above

Display Logic: If (a. Yes, with consistent or predictable change) or (b. Yes, with inconsistent and unpredictable change) is selected for "Have you noticed that your Parkinson's symptoms change during your period?"

30. In the prior question, you selected the following thinking, feeling, and sleep symptoms because you notice a change during your period. Please select how you feel these symptoms have changed.

Display Logic: If (p. None of the above) is NOT selected for "Which Parkinson's **thinking, feeling, and sleep** symptoms change during your period?"

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer
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Display Logic: If any symptom is selected for any item in “Which Parkinson’s disease related **thinking, feeling, and sleep** symptoms **change** during your period?”, corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

31. Which other Parkinson’s **related** symptoms **change** during your period?

Please select all that apply.

- a. Urinary problems – feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure – feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation – fewer than three bowel movements a week or having to strain to pass a stool
- d. Decreased speed of digestion, bloating, reflux
- e. Sweating problems – excessive perspiration, even when not hot or anxious
- f. Drooling – buildup of saliva because of decreased swallowing
- g. Dry mouth
- h. Nausea
- i. Sexual problems – decreased libido or pain
- j. Smell loss – decreased ability to detect odors
- k. Changes to sense of taste
- l. Pain – discomfort in one body part or the entire body
- m. Tingling, prickling or numbness of the skin
- n. Speech problems – speaking in a soft and monotone voice and sometimes slurring words or mumbling
- o. Visual problems
- p. None of the above

Display Logic: If (a. Yes, with consistent or predictable change) or (b. Yes, with inconsistent and unpredictable change) is selected for “Have you noticed that your Parkinson’s symptoms change during your period?”

32. In the prior question, you selected the following Parkinson’s related symptoms because you notice a change during your period. Please select how you feel these symptoms have changed.

Display Logic: If (p. None of the above) is NOT selected for “Which Parkinson’s related symptoms change during your period?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer
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Display Logic: If any symptom is selected for any item in “Which Parkinson’s disease related symptoms **change** during your period?”, corresponding item will be displayed in this matrix.

Multiple choice, single answer, required

33. Do you currently take medication for Parkinson's disease?

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

Multiple choice, single answer, required

34. Is your PD medication less effective the week before your period when compared to other points in your menstrual cycle?

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

Display Logic: If (a. Yes) is selected for "Do you currently take medication for Parkinson's disease?"

Numerical response limited to 0-7, required

35. For how many days during the week before your period do you feel your PD medication is less effective? If you are not sure, please make your best guess.

Number of days: _____

Display Logic: If (a. Yes) or (b. Sometimes) is selected for "Is your PD medication as effective the week before your period when compared to other points in your menstrual cycle?"

Multiple choice, single answer, required

36. Do you feel your PD medication less effective during your period when compared to other points in your menstrual cycle?

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

Display Logic: If (a. Yes) is selected for "Do you currently take medication for Parkinson's disease?"

Numerical response limited to 0-14 required

37. For how many days during your period is your PD medication less effective? If you are not sure, please make your best guess.

Number of days: _____

Display Logic: If (a. Yes) or (b. Sometimes) is selected "Is your PD medication less effective during your period?"

Multiple choice, single answer, required

38. Is your PD medication less effective just after the end of your period when compared to other points in your menstrual cycle?

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

Display Logic: If (a. Yes) is selected for “Do you currently take medication for Parkinson’s disease?”

Numerical response limited to 0-7, required

39. For how many days just after the end of your period is your PD medication less effective? If you are not sure, please make your best guess.

Number of days: ____

Display Logic: If (a. Yes) or (b. Sometimes) is selected for “Is your PD medication less effective just after the end of your period when compared to other points in your menstrual cycle?”

Multiple choice, single answer, required

40. Do you choose to change your PD medication to maintain function and provide relief at any time during your cycle, when you feel your symptoms are more bothersome?
- a. Yes, I increase the dose, with good effect
 - b. Yes, I increase the dose, with no effect
 - c. Yes, I reduce the dose
 - d. No change
 - e. Don't have enough medication to increase dose, but would like to
 - f. Not sure
 - g. Prefer not to answer

Display Logic: If (a. Yes) or (b. Sometimes) is selected for “Is your PD medication less effective just after the end of your period when compared to other points in your menstrual cycle?”

Multiple choice, single answer, required

41. Do you talk to your healthcare team to make these changes to your PD medication?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Display Logic: If (a. Yes, I increase the dose, with good effect), (b. Yes, I increase the dose, with no effect), or (c. Yes, I reduced the dose) is selected for “Do you choose to change your PD medication to maintain function and provide relief at any time during your cycle, when you feel your symptoms are more bothersome?”

Multiple choice, single answer, required

42. Does this change to your Parkinson’s medication result in any side effects (nausea, dyskinesia, fatigue, drowsiness, change in impulse control, etc.)?
- a. Yes
 - b. Sometimes
 - c. No
 - d. Not sure
 - e. Prefer not to answer

The next set of questions are about the types of feminine products you typically use.

Multiple choice, multiple answer, required

43. I typically use:
Please select all that apply.
- a. Tampons

- b. Pads/Feminine Napkins
- c. Menstrual cup or similar product
- d. Period panties
- e. Other
- f. Not applicable
- g. Not sure
- h. Prefer not to answer

Multiple choice, single answer, required

44. Do you find that your motor symptoms make using feminine products more difficult?

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

Multiple choice, multiple answer, required

45. Due to difficulties in use, I am considering changing to:

Please select all that apply.

- a. Tampons
- b. Pads/Feminine Napkins
- c. Menstrual cup or similar product
- d. Period Panties
- e. Other
- f. Not applicable
- g. Not sure
- h. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you find that your motor symptoms make using feminine products more difficult?”

In the next section, we would like to understand more about your reproductive history.

46. Have you successfully conceived or tried to conceive?

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

End of Survey thank you:

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.**

PERIMENOPAUSE

47. Has your perimenopausal or menopausal status been diagnosed by a healthcare professional?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer
48. Are you in perimenopause (having irregular cycles, fluctuation in hormone levels but have had at least one period in the last year)?
- a. Yes
 - b. Surgically induced
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, multiple answers, required

49. Have you experienced any of the following perimenopausal symptoms? Please select all that apply.

- a. Changes in your periods (heavier or lighter than normal)
- b. Irregular periods
- c. Hot flashes/flushes
- d. Sweating
- e. Sleep disturbances
- f. Mood swings
- g. Anxiety
- h. Depression
- i. Worsening PMS
- j. Breast tenderness
- k. Weight gain
- l. Hair changes
- m. Heart palpitations
- n. Headaches
- o. Loss of sex drive
- p. pain with intercourse
- q. Difficulty concentrating
- r. Forgetfulness
- s. Muscle pain
- t. Urinary infections or pain with urination
- u. Urinary frequency
- v. Incontinence
- w. Spotty or greasy skin/hair
- x. Other
- y. None of the above
- z. Not sure
- a. Prefer not to answer

50. Are you currently experiencing perimenopausal symptoms?

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

Multiple choice, single answer, required

51. Have you experienced any changes in your Parkinson's symptoms during perimenopause?
- a. Yes
 - b. No
 - c. Not sure
 - d. Prefer not to answer

Multiple choice, multiple answer, required

52. Which Parkinson's **movement** symptoms **change** during perimenopause? Please select all that apply.

We recognize that it may be difficult to differentiate between peri-menopausal and Parkinson's symptoms, please complete to the best of your ability.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time – period during which PD medication(s) do not work as well
- j. Dyskinesia – uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. Restless legs – irresistible urge to move your legs
- l. Cramping and dystonia – involuntary muscle contractions, sometimes causing slow repetitive or twisting movements
- m. None of the above

Display Logic: If (a. Yes) is selected for “Have you experienced any changes in your Parkinson's symptoms during perimenopause?”

53. In the prior question, you selected the following Parkinson's movement symptoms because you notice a change in those symptoms during perimenopause. Please select how you feel these symptoms change.

Display Logic: If (m. None of the above) is NOT selected for “Which Parkinson's movement symptoms change during perimenopause?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in “Which Parkinson's **movement** symptoms **change** during perimenopause?”, corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

Which Parkinson's **thinking, feeling, and sleep** symptoms **change** during perimenopause? Please select all that apply.

We recognize that it may be difficult to differentiate between peri-menopausal and Parkinson's symptoms, please complete to the best of your ability.

- a. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- b. Trouble staying awake during the daytime
- c. Acting out your dreams while asleep – punching, flailing your arms in the air, making running movements, etc.
- d. Trouble thinking clearly, remembering things, and being attentive
- e. Memory loss- trouble remembering things
- f. Confusion – not knowing where you are, the date/time, who familiar people are
- g. Hallucinations – hearing, seeing, feeling, tasting, or smelling something that is not really there
- h. Anxiety – feeling nervous, worried, or tense more than usual and/or panic attacks
- i. Depression – periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue – physical and mental state of having extremely low energy
- k. Apathy – decreased motivation, initiative, or spontaneity
- l. Irritability and frustration
- m. Paranoia or suspicion – having false, often paranoid, beliefs (delusions), such as that a spouse is being unfaithful, or money is being stolen
- n. Obsessive and unreasonable thoughts and fears
- o. Inability to control impulsive urges
- p. None of the above

54.

Display Logic: If (a. Yes) is selected for “Did you/do you experience any changes in your Parkinson's symptoms during perimenopause?”

55. In the prior question, you selected the following thinking, feeling, and sleep symptoms because you notice a change during perimenopause. Please select how you feel these symptoms have changed.

Display Logic: If (p. None of the above) is NOT selected for “Which Parkinson's **thinking, feeling, and sleep** symptoms change during perimenopause?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in “Which Parkinson's **thinking, feeling, and sleep** symptoms **change** during perimenopause?”, corresponding item will be displayed in this matrix.

Multiple choice, multiple answer, required

56. Which other Parkinson's **related** symptoms **change** during perimenopause? We recognize that it may be difficult to differentiate between peri-menopausal and Parkinson's symptoms, please complete to the best of your ability. Please select all that apply.

- a. Urinary problems – feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure – feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation – fewer than three bowel movements a week or having to strain to pass a stool
- d. Decreased speed of digestion, bloating, reflux
- e. Sweating problems – excessive perspiration, even when not hot or anxious
- f. Drooling – buildup of saliva because of decreased swallowing
- g. Dry mouth
- h. Nausea
- i. Sexual problems – decreased libido or pain
- j. Smell loss – decreased ability to detect odors
- k. Changes to sense of taste
- l. Pain – discomfort in one body part or the entire body
- m. Tingling, prickling or numbness of the skin
- n. Speech problems – speaking in a soft and monotone voice and sometimes slurring words or mumbling
- o. Visual problems
- p. None of the above

Display Logic: If (a. Yes) is selected for “Did you/do you experience any changes in your Parkinson's symptoms during perimenopause?”

57. In the prior question, you selected the following Parkinson's related symptoms because you notice a change during perimenopause. Please select how you feel these symptoms have changed.

Display Logic: If (p. None of the above) is NOT selected for “Which Parkinson's related symptoms change during perimenopause?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in “Which other Parkinson's **related** symptoms **change** during perimenopause?”, corresponding item will be displayed in this matrix.

Multiple choice, single answer, required

58. Do you currently take medication for Parkinson's disease?

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

59. When you have a period, is your PD medication as effective during your period when compared to other points in your menstrual cycle?

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

Display Logic: If (a. Yes) is selected for “Do you take medication for Parkinson’s disease?”

60. Has your PD medication been as effective during perimenopause compared to pre-menopause?

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

Display Logic: If (a. Yes) is selected for “Do you take medication for Parkinson’s disease?”

Multiple choice, single answer, required

61. Do you choose to change your PD medication to maintain function and provide relief at any time during your menstrual cycle, when you feel your symptoms are more bothersome?

- a. Yes, I increase the dose, with good effect
- b. Yes, I increase the dose, with no effect
- c. Yes, I reduce the dose
- d. No change
- e. Don’t have enough medication to increase dose but would like to
- f. Not sure
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for “Do you currently take medication for Parkinson’s disease?”

Multiple choice, single answer, required

62. Did you talk to your Parkinson’s healthcare team to make these changes to your PD medication changes?

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

Display Logic: If (a. Yes) is selected for “Do you currently take medication for Parkinson’s disease?”

In the next section, we would like to understand more about your reproductive history.

63. Have you successfully conceived or tried to conceive?

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

End of Survey thank you:

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.**

POST MENOPAUSE

Your prior answers indicate you are in menopause. We will now ask you questions about your experiences in this life phase.

Text box, numerical response limited to 0-99, required

64. Approximately what age were you when you became post-menopausal? If you are not sure, please make your best guess.

Age: _____

Multiple choice, multiple answer, required

65. Which Parkinson's **movement symptoms** do you experience now?

Please select all that apply.

- a. Problems with walking
- b. Problems with balance
- c. Problems with falling
- d. Shaking or tremor
- e. Slow movements
- f. Stiffness
- g. Problems swallowing pills
- h. Problems eating meals
- i. OFF time – period during which PD medication(s) do not work as well
- j. Dyskinesia – uncontrolled, involuntary movements such as fidgeting, writhing, wriggling, head bobbing, or body swaying
- k. Restless legs – irresistible urge to move your legs
- l. Cramping and dystonia – involuntary muscle contractions, sometimes causing slow repetitive or twisting movements
- m. None of the above

66. In the prior question, you selected the following Parkinson's movement symptoms because you experience them now. Please select how you feel these symptoms **changed after menopause**.

Display Logic: If (m. None of the above) is NOT selected for "Which Parkinson's movement symptoms do you experience now?"

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in "Which Parkinson's **movement symptoms** do you experience now?", corresponding item will be displayed in this matrix, AND if "After surgical or medically induced menopause" AND "After natural menopause" is not selected for "My Parkinson's was diagnosed:"

Multiple choice, multiple answer, required

67. Which Parkinson's **thinking, feeling, and sleep symptoms** do you experience now?

Please select all that apply.

- a. Difficulty sleeping- trouble getting to sleep or staying asleep through the night (insomnia)
- b. Trouble staying awake during the daytime
- c. Acting out your dreams while asleep – punching, flailing your arms in the air, making running movements, etc.
- d. Trouble thinking clearly, remembering things, and being attentive
- e. Memory loss- trouble remembering things
- f. Confusion – not knowing where you are, the date/time, who familiar people are
- g. Hallucinations – hearing, seeing, feeling, tasting, or smelling something that is not really there
- h. Anxiety – feeling nervous, worried, or tense more than usual and/or panic attacks
- i. Depression – periods of sadness, hopelessness, emptiness, or loss of enjoyment
- j. Fatigue – physical and mental state of having extremely low energy
- k. Apathy – decreased motivation, initiative, or spontaneity
- l. Irritability and frustration
- m. Paranoia or suspicion – having false, often paranoid, beliefs (delusions), such as that a spouse is being unfaithful, or money is being stolen
- n. Obsessive and unreasonable thoughts and fears
- o. Inability to control impulsive urges
- p. None of the above

68. In the prior question, you selected the following thinking, feeling, and sleep symptoms because you experience them now. Please select how you feel these symptoms **changed after menopause**.

Display Logic: If (p. None of the above) is NOT selected for “Which Parkinson’s **thinking, feeling, and sleep** do you experience now?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in “Which Parkinson’s **thinking, feeling, and sleep symptoms** do you experience now?”, corresponding item will be displayed in this matrix, AND if “After surgical or medically induced menopause” AND “After natural menopause” is not selected for “My Parkinson’s was diagnosed:”

Multiple choice, multiple answer, required

69. Which other Parkinson’s **related symptoms** do you experience now?

Please select all that apply.

- a. Urinary problems – feeling an urgent need to urinate, a need to urinate too often, or having urine accidents
- b. Low blood pressure – feeling light-headed when standing up or sitting up after lying down, sitting, or squatting
- c. Constipation – fewer than three bowel movements a week or having to strain to pass a stool
- d. Decreased speed of digestion, bloating, reflux
- e. Sweating problems – excessive perspiration, even when not hot or anxious
- f. Drooling – buildup of saliva because of decreased swallowing

- g. Dry mouth
- h. Nausea
- i. Sexual problems – decreased libido or pain
- j. Smell loss – decreased ability to detect odors
- k. Changes to sense of taste
- l. Pain – discomfort in one body part or the entire body
- m. Tingling, prickling or numbness of the skin
- n. Speech problems – speaking in a soft and monotone voice and sometimes slurring words or mumbling
- o. Visual problems
- p. None of the above

70. In the prior question, you selected the following Parkinson’s related symptoms because you experience them now. Please select how you feel these symptoms **changed after menopause**.
Display Logic: If (p. None of the above) is NOT selected for “Which Parkinson’s related symptoms do you experience now?”

Symptom	a. Much better	b. Better	c. Neutral	d. Worse	e. Much worse	f. Not sure	g. Prefer not to answer

Display Logic: If any symptom is selected for any item in “Which other Parkinson’s **related symptoms** do you experience now?”, corresponding item will be displayed in this matrix, AND if “After surgical or medically induced menopause” AND “After natural menopause” is not selected for “My Parkinson’s was diagnosed:”

In the next section, we would like to understand more about your reproductive history.

71. Have you successfully conceived or tried to conceive?
- a. Yes
 - b. No
 - c. Prefer not to answer

End of Survey thank you:

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.**

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.**