

Initial Questionnaire PD Exercise Programme

PwP

Study Title Assessing the Impact of Exercise Classes on Non-Motor Symptoms in People with Parkinson's during the COVID-19 Pandemic.

Please enter your email address *required to answer the survey.

Part 1. A bit about You.

To which gender do you most identify?

- Male
- Female
- Transgender male
- Transgender female
- Non-binary/Non-conforming
- Prefer not to answer
- Other

What is your age in years?

- Under 30
- 31-34
- 35-40
- 41-44
- 45-50
- 51-54
- 55-60
- 61-64
- 65-70
- 71-74
- 75-80
- Over 80

Which Province are you currently in?

- Munster: Clare, Cork, Kerry, Limerick, Tipperary and Waterford.
- Connacht: Galway, Leitrim, Mayo, Roscommon and Sligo.
- Leinster: Carlow, Dublin, Kildare, Kilkenny, Laois, Longford, Louth, Meath, Offaly, Westmeath, Wexford and Wicklow.
- Ulster: Cavan, Monaghan and Donegal.

Part 2. A Bit about your exercise and daily activity. Over the past month, please select the statement below you most agree with.

Do you have access to the internet in your own home, either on smartphone or computer?

- Yes
- No

Which exercise programme are you currently involved in? (You can choose more than one option)

- PD Rebels
- PD Warriors
- Music Movement Therapy
- Rock Steady Boxing
- PD Smoveys
- Galway PD Association Physio Classes
- Other.....

How do you attend these classes?

- Online
- In person
- Mix of both online classes or in person
- Other.....

How long have you been attending these classes?

- > 1 month
- 1-3 months
- 3-6 months
- 6 months – 1 year
- 1 year -2 years
- > 2 years

Which statement best describes your exercise and activity?

- I exercise every day
- I exercise every second day
- I exercise a few times a week
- I exercise once a week
- I exercise once every two weeks
- I never exercise

Do you exercise more or less often than before the current COVID-19 lockdowns?

- Exercise more now
- Exercise the same amount
- Exercise less now

What is the greatest benefit you have found from attending these classes? (You can choose more than one option.

- The classes have helped with my motor problems associated with my Parkinsons
- The classes have helped with my sleep
- The classes have helped with my mood or any anxiety
- The classes have helped with my diet and bowel movements
- The classes have helped with my motivation
- The classes provide a social interaction for me
- Other.....

Part 3. A bit about the COVID-19 pandemic and Lockdown situation. Please answer the following questions, thinking back over the past month.

What is the current level of lockdown where you live at the moment?

- Level 1
- Level 2
- Level 3
- Level 4
- Level 5

Has your permanent residence changed due to COVID-19 virus?

- Yes
- No
- Not applicable

How serious do you think the COVID-19 virus is in your county?

- Very serious
- Serious
- Neutral
- Not very serious
- Not serious at all

How often do you update yourself about the COVID-19 virus?

- Several times a day
- Daily
- Every second day
- A few times a week
- Once a week/Never
- Not applicable

Do you live with people deemed high risk for COVID-19?

- Yes, others in my household

- Yes, Myself
- Yes, Myself and others in my household
- No
- Not applicable

Have you had a positive test for the COVID-19 virus?

- Yes
- No
- Not sure

Has anyone you live with had a positive test for the COVID-19 virus?

- Yes
- No
- Not sure

Do you worry about getting the COVID-19 virus?

- Very much
- Much
- Somewhat
- A little
- Not at all
- Not applicable

Have you received the COVID-19 vaccine?

- Yes
- No
- Not sure

Which of the COVID-19 vaccines have you received?

- AstraZenca Vaccine
- Moderna Vaccine
- Pfizer Vaccine
- Not applicable
- Not sure

Part 4. A bit about your Parkinson's Disease history and medications and other medications you might be on. Please answer the following questions thinking back over the past month.

How many years since your first Parkinson's Disease symptom? (i.e. first time you noticed a symptom such as tremor in hand or slowness or stiffness when you were moving.)

- 0-5

- 6-10
- 11-15
- 16-20
- 20-25
- 26-30
- 30+

How many years since your diagnosis of Parkinson's Disease? (i.e. when you went to the GP or Neurologist and they told you that you had Parkinson's Disease.)

- 0-5
- 6-10
- 11-15
- 16-20
- 20-25
- 26-30
- 30+

Please indicate which medications you are on for your Parkinson's Disease below. (You can choose more than one option).

- Carbidopa-levodopa (e.g. Sinemet)
- Inhaled carbidopa-levodopa (e.g. Inbrija)
- Dopamine agonists (e.g. Requip, Neurpro, Mirapexin)
- MAO B inhibitors (e.g. Eldepryl, Azilect, Rasagiline)
- Catechol O-methyltransferase (COMT) inhibitors (e.g. Comtess, Stalevo)
- Anticholinergics (e.g. Kemadrin, Trihexiphenidyl, Orphenadrine)
- Amantadine
- Other (please elaborate)

Have you ever undergone any surgical procedures for your Parkinson's Disease ?

- Deep Brain Stimulation (DBS)
- Carbidopa-levodopa infusion (e.g. Duodopa)
- Other (please elaborate)

Some medications can make you feel drowsy even if they are not being prescribed for sleep problems. Are you taking any of the following medications that could make you feel drowsy or affect your sleep?

- Antidepressants
- Medicines for anxiety
- Medicines for sleep problems

- Medicines for pain (nerve pain or other types of pain)
- Other (please elaborate)

If you answered yes to the above question and know the name of your medicine, please enter the name here:

Part 5. Due to having Parkinson's disease, how often during the past month have you....

Had difficulty doing the leisure activities which you would like to do?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty looking after your home, e.g. DIY, housework, cooking?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty carrying bags of shopping?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems walking half a mile?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems walking 100 yards?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems getting around the house as easily as you would like?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty getting around in public?

- Never
- Occasionally
- Sometimes
- Often
- Always

Needed someone else to accompany you when you went out?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt frightened or worried about falling over in public?

- Never
- Occasionally
- Sometimes
- Often
- Always

Been confined to the house more than you would like?

- Never

- Occasionally
- Sometimes
- Often
- Always

Had difficulty washing yourself?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty dressing yourself?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems doing up your shoe laces?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems writing clearly?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty cutting up your food?

- Never
- Occasionally

- Sometimes
- Often
- Always

Had difficulty holding a drink without spilling it?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt depressed?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt isolated and lonely?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt weepy or tearful?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt angry or bitter?

- Never
- Occasionally
- Sometimes

- Often
- Always

Felt anxious?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt worried about your future?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt you had to conceal your Parkinson's from people?

- Never
- Occasionally
- Sometimes
- Often
- Always

Avoided situations which involve eating or drinking in public?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt embarrassed in public due to having Parkinson's disease?

- Never
- Occasionally
- Sometimes
- Often

- Always

Felt worried by other people's reaction to you?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems with your close personal relationships?

- Never
- Occasionally
- Sometimes
- Often
- Always

Lacked support in the ways you need from your spouse or partner?

- Never
- Occasionally
- Sometimes
- Often
- Always

Lacked support in the ways you need from your family or close friends?

- Never
- Occasionally
- Sometimes
- Often
- Always

Unexpectedly fallen asleep during the day?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had problems with your concentration, e.g. when reading or watching TV?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt your memory was bad?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had distressing dreams or hallucinations?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had difficulty with your speech?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt unable to communicate with people properly?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt ignored by people?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had painful muscle cramps or spasms?

- Never
- Occasionally
- Sometimes
- Often
- Always

Had aches and pains in your joints or body?

- Never
- Occasionally
- Sometimes
- Often
- Always

Felt unpleasantly hot or cold?

- Never
- Occasionally
- Sometimes
- Often
- Always

Suffered from Constipation?

- Never
- Occasionally
- Sometimes
- Often
- Always

Part 6: A bit about your mood. If any concerns are raised for you as a result of the following questions please contact your own GP or Neurologist. The contact details for the Samaritans are a free 24 hour telephone number: 116 123, email jo@samaritans.ie or through the Samaritans Self-Help App. Please answer the following questions, thinking about over the past month.

I feel tense or 'wound up

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

I can laugh and see the funny side of things

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through my mind

- A great deal of the time
- A lot of the time
- From time to time, but not too often
- Only occasionally

I feel cheerful

- Not at all
- Not often
- Sometimes
- Most of the time

I can sit at ease and feel relaxed

- Definitely
- Usually
- Not Often
- Not at all

I feel as if I am slowed down

- Nearly all the time
- Very often
- Sometimes
- Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach

- Not at all
- Occasionally
- Quite Often
- Very Often

I have lost interest in my appearance

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as I have to be on the move

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV program

- Often
- Sometimes
- Not often
- Very seldom

Part 7: A bit about your Sleep. The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

During the past month, what time have you usually gone to bed at night? _____ (am /pm)_____

- During the past month, how long (in minutes) has it usually taken you to fall asleep each night? _____(mins)_____
- During the past month, what time have you usually gotten up in the morning? _____(am/pm)_____
- During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.) _____(hrs)_____

During the past month, how often have you had trouble sleeping because you...

Cannot get to sleep within 30 minutes

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Wake up in the middle of the night or early morning

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Have to get up to use the bathroom

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Cannot breathe comfortably

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Cough or snore loudly

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Feel too cold

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Feel too hot

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Have bad dreams

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Have pain

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Other reason(s), please describe:

During the past month, how often have you taken medicine to help you sleep (prescribed or “over the counter”)?

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

During the past month, how often have you had trouble staying awake while driving, eating meals,

or engaging in social activity?

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

- No problem at all
- Only a very slight problem
- Somewhat of a problem
- A very big problem

During the past month, how would you rate your sleep quality overall?

- Very good
- Fairly good
- Fairly bad
- Very bad

Do you have a bed partner or room mate?

- No bed partner or room mate
- Partner/room mate in other room
- Partner in same room but not same bed

- Partner in same bed

If you have a room mate or bed partner, ask him/her how often in the past month you have had:

Loud snoring

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Long pauses between breaths while asleep

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Legs twitching or jerking while you sleep

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Episodes of disorientation or confusion during sleep

- Not during the past month
- Less than once a week
- Once or twice a week
- Three or more times a week

Other restlessness while you sleep, please describe:

Questionnaire complete.

Thank you for completing this questionnaire. We appreciate your help with our research.