

Understanding Fatigue in Parkinson's Patients

Survey Flow

EmbeddedData

ExternalDataReferenceValue will be set from Panel or URL.
RefererValue will be set from Panel or URL.

Branch: New Branch

If
 If Referer Contains foxinsight.michaeljfox.org
 Or Referer Contains foxinsight.org
Elseif
 If Referer Contains qualtrics
 And Q_URL Contains preview
Elseif
 If Referer Contains survey.foxinsight.org
 And Q_URL Contains previews

Authenticator: Single Sign On - Token

EmbeddedData

Fox Insight User ID = \${m://ExternalDataReference}

Standard: Introduction (3 Questions)

Branch: New Branch

If
 If There are many ways in which to define fatigue. For the purpose of this survey, please think of f... Never Is Selected

BlockRandomizer: 3 -

Block: Parkinson's Disease Fatigue Scale (1 Question)
Standard: SCOPA SLEEP (18 Questions)
Standard: Apathy Scale (1 Question)

EndSurvey:

Branch: New Branch

If
 If There are many ways in which to define fatigue. For the purpose of this survey, please think of f... Less often than monthly Is Selected
 Or There are many ways in which to define fatigue. For the purpose of this survey, please think of f... Once a month Is Selected
 Or There are many ways in which to define fatigue. For the purpose of this survey, please think of f... A few times a month Is Selected
 Or There are many ways in which to define fatigue. For the purpose of this survey, please think of f... Once a week Is Selected
 Or There are many ways in which to define fatigue. For the purpose of this survey, please think of f... A few times a week Is Selected

Or There are many ways in which to define fatigue. For the purpose of this survey, please think of f... Every day Is Selected

Standard: 1 (1 Question)
Standard: 2 (6 Questions)
Standard: Block 13 (1 Question)
Standard: 3.1 (1 Question)
Standard: 3.2 (1 Question)
Standard: 4 (4 Questions)
Block: 5 (2 Questions)
Standard: 6 (1 Question)
Standard: 7 (8 Questions)

BlockRandomizer: 4 -

Standard: Modified Fatigue Impact Scale (1 Question)
Block: Parkinson's Disease Fatigue Scale (1 Question)
Standard: SCOPA SLEEP (18 Questions)
Standard: Apathy Scale (1 Question)

EndSurvey:

Page Break

Start of Block: Introduction

Q1 The Michael J. Fox Foundation for Parkinson's Research (MJFF) seeks to understand unmet needs of Parkinson's patients. With this goal, the current research explores how patients experience, and communicate about, their life with Parkinson's disease (PD). In particular, the current research focuses on fatigue in PD.

Page Break

Q2 How do you define fatigue? Please provide your definition in the space below.

Page Break

Q3 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.*

How frequently, if ever, do you experience fatigue?

- Every day (1)
- A few times a week (2)
- Once a week (3)
- A few times a month (4)
- Once a month (5)
- Less often than monthly (6)
- Never (7)

Page Break

End of Block: Introduction

Start of Block: Parkinson's Disease Fatigue Scale

Q4

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

Printed below are a series of statements about fatigue and the impact that it can have.

How well do the statements describe your own feelings and experiences over the past two weeks?

Read each item and decide how much you agree or disagree with it. Then tick the appropriate box.

Tick only one box for each item and try not to miss any out.

	Strongly disagree (1)	Disagree (2)	Do not agree or disagree (3)	Agree (4)	Strongly agree (5)
I have to rest during the day (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My life is restricted by fatigue (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get tired more quickly than other people I know (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue is one of my three worst symptoms (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel completely exhausted (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue makes me reluctant to socialise (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

It takes me longer to get things done because of fatigue (7)

I have a feeling of heaviness (8)

If I wasn't so tired I could do more things (9)

Everything I do is an effort (10)

I feel tired for much of the time (11)

I feel totally drained (12)

Fatigue makes it difficult for me to cope with everyday activities (13)

I feel tired even when I haven't done anything (14)

Because of fatigue I do less in my day than I would like (15)

I get so tired I want to lie down wherever I am (16)

Start of Block: SCOPA SLEEP

Q5 By means of this questionnaire, we would like to find out to what extent *in the past month* you have had problems with sleeping. Some of the questions are about problems with sleeping *at night*, such as, for example, not being able to fall asleep or not managing to sleep on. Another set of questions is about problems with sleeping *during the day*, such as dozing off (too) easily and having trouble staying awake.

Q6 Use of sleeping tablets

Q7 How often did you use sleeping tablets in the last months? (prescribed by a physician or not)

- not at all (1)
 - less than once a week (2)
 - once or twice a week (3)
 - more than 3 times a week (4)
-

Page Break

Display This Question:

If Q7 = less than once a week

Or Q7 = once or twice a week

Or Q7 = more than 3 times a week

Q8 Which sleeping tablets did you use in the last month?

	Medication 1 (4)	Medication 2 (5)	Medication 3 (6)
name: (1)			
amount per month: (2)			
dose per tablet: (3)			

Page Break

Q9 Sleeping at night

The questions below are for everyone and concern sleeping at night. If you have been using sleeping tablets, then the answer should reflect how you have slept while taking these tablets.

Q10 In the past month, have you had trouble falling asleep when you went to bed at night?

- not at all (1)
 - a little (2)
 - quite a bit (3)
 - a lot (4)
-

Q11 In the past month, to what extent do you feel that you have woken *too often*?

- not at all (1)
 - a little (2)
 - quite a bit (3)
 - a lot (4)
-

Q12 In the past month, to what extent do you feel that you have been lying awake for *too long* at night?

- not at all (1)
 - a little (2)
 - quite a bit (3)
 - a lot (4)
-

Q13 In the past month, to what extent do you feel that you have woken up *too early* in the morning?

- not at all (1)
 - a little (2)
 - quite a bit (3)
 - a lot (4)
-

Q14 In the past month, to what extent do you feel you have had *too little* sleep at night?

- not at all (1)
 - a little (2)
 - quite a bit (3)
 - a lot (4)
-

Q15 Overall, how well have you slept at night during the past month?

- Very well (1)
- well (2)
- rather well (3)
- not well but not badly (4)
- rather badly (5)
- badly (6)
- very badly (7)

Page Break

Q16 Sleeping during the day and the evening

Q17 How often in the past month have you fallen asleep unexpectedly either during the day or in the evening?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Q18 How often in the past month have you fallen asleep while sitting peacefully?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Q19 How often in the past month have you fallen asleep while watching TV or reading?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Q20 How often in the past month have you fallen asleep while talking to someone?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Q21 In the past month, have you had trouble staying awake during the day or in the evening?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Q22 In the past month, have you experienced falling asleep during the day as a problem?

- never (1)
 - sometimes (2)
 - regularly (3)
 - often (4)
-

Page Break

End of Block: SCOPA SLEEP

Start of Block: Apathy Scale

Q23 Thinking about the **past week**, please answer the following questions.

	Not at all (1)	Slightly (2)	Some (3)	A lot (4)
Are you interested in learning new things? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does anything interest you? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you concerned about your condition? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you put much effort into things? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you always looking for something to do? (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have plans and goals for the future? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have motivation? (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have the energy for daily activities? (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Does someone have to tell you what to do each day? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you indifferent to things? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you unconcerned with many things? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you need a push to get started on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

things? (12)

Are you neither
happy nor sad,
just in between?
(13)

Would you
consider yourself
apathetic? (14)

Page Break

Start of Block: 1

Q24 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.*

When you experience fatigue, in general, how long does a period of fatigue last for you?

- Less than 1 hour (1)
- 1 hour or less than 6 hours (2)
- 6 hours or less than 1 full day (24 hours) (3)
- 1 full day (24 hours) or longer (4)
- I always feel fatigued (6)

Page Break

End of Block: 1

Start of Block: 2

Q25

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".

When you experience fatigue, do you feel sleepy?

Yes (1)

No (2)

Page Break

Q26

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

When you experience fatigue, do you feel weakness?

Yes (1)

No (2)

Page Break

Q27

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

When you experience fatigue, do you feel a sensation of heaviness (feel weighted down)?

Yes (1)

No (2)

Page Break

Q28

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

When you experience fatigue, do you feel aching?

Yes (1)

No (2)

Page Break

Q29

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

When you experience fatigue, do you feel stiffness?

Yes (1)

No (2)

Page Break

Q55

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

When you experience fatigue, do you feel some other way from a physical point of view?

Yes (1)

No (2)

Page Break

End of Block: 2

Start of Block: Block 13

Display This Question:

If Q55 = Yes

Q56

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".

Please describe how you feel from a physical point of view when you experience fatigue.

End of Block: Block 13

Start of Block: 3.1



Q30 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.*

When you experience fatigue, what does it most often feel like from a **cognitive** point of view? *By cognitive we mean your thinking, memory, reasoning, attention or concentration.*

Please select up to three.

- An inability to think clearly (1)
- Difficulty concentrating (3)
- Trouble communicating (e.g., difficulty in finding the right words) (4)
- Struggling in following directions and/or conversations (5)
- Short term memory problems (e.g., forgetfulness) (6)
- Some other way from a cognitive point of view (Please specify in the box below)
(7) _____
- I don't experience cognitive difficulties when I am fatigued (8)

Page Break



Q31 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.*

When you are fatigued, which **emotion(s)**, if any, do you experience most often along with your fatigue?

Please select up to three.

- Overwhelmed (1)
- Frustration (2)
- Anger (3)
- Irritability (4)
- Anxiety (5)
- Fear (6)
- Depression and/or sadness (7)
- Another emotion (Please specify in the box below) (8)

- I do not experience emotions along with my fatigue (9)



Q32

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

Which of the following experiences, if any, can trigger or bring on fatigue for you?

Please select all that apply.

- A poor night’s sleep (1)
- Physical exertion (e.g., from strenuous exercise or participating in sports) (2)
- Emotions, either negative or positive (such as stress, anger, joy, excitement, etc.) (3)
- Being overheated (4)
- Taking medication for Parkinson’s disease (5)
- A busy day (8)
- Some other trigger(s) (Please specify in the box below) (6)

- Fatigue is not triggered by specific experiences for me (7)

Q33 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.*

When you experience fatigue, how often, if ever, do your other PD symptoms (e.g., rigidity or tremors) get worse?

- Always (1)
- Most of the time (2)
- Sometimes (3)
- Rarely (4)
- Never (5)

Page Break

Q34 Many individuals with Parkinson's disease (PD) fluctuate between periods in which their symptoms are better controlled and periods during which symptoms return. We refer to the periods during which symptoms are better controlled as ON, and periods during which symptoms return as OFF. Based on this definition of OFF, do you experience OFF periods?

Yes (1)

No (2)

Page Break

Display This Question:

If Q34 = Yes



Q35 *There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".*

We refer to the periods during which symptoms are better controlled as ON, and periods during which symptoms return as OFF. Which of the following statements comes closest to your experience?

- I am more likely to experience fatigue during OFF periods than during ON periods (1)
- I am more likely to experience fatigue during ON periods than during OFF periods (2)
- There is no relationship between fatigue and OFF for me - I am just as likely to experience fatigue during an OFF or ON period (3)

Page Break



Q36

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".

When you experience fatigue, what strategies do you most often use to cope with or recover from your fatigue?

Please select up to three strategies.

- Sitting quietly (e.g., watching television, listening to the radio, reading, etc.) (1)
 - Sleeping (2)
 - Laying down to rest (not sleeping) (3)
 - Exercising (4)
 - Meditating (5)
 - Sitting in a bath and/or a jacuzzi (6)
 - Drinking coffee/caffeine (7)
 - Taking medication (8)
 - Eating (10)
 - Some other coping strategy (Please specify in the box below) (9)
-

Display This Question:

If Q36 = Taking medication

Q37

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

Which medication(s) do you most often take to cope with or recover from your fatigue?

Please select all that apply.

- Carbidopa-Levodopa (Sinemet, Sinemet CR, Sinemet Extended Release, Parcopa, Rytary, Stalevo, Duopa) (1)
 - Entacapone (Comtan) (2)
 - Pramipexole (Mirapex or Mirapex ER) (3)
 - Ropinirole (Requip or Requip XL) (4)
 - Rotigotine (Neupro patch) (5)
 - Apomorphine (apokyn) (6)
 - Amantadine (Symmetrel or Gocovri) (7)
 - Safinamide (Xadago) (8)
 - Selegiline (Deprenyl, Eldepryl, Zelapar) (9)
 - Another medication (Please specify in the box below) (10)
-

Page Break

End of Block: 5

Start of Block: 6

Q38

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".

How often does  help you cope with or recover from your fatigue?

- Usually (75-100% of the time) (1)
- Often (50-74% of the time) (2)
- Sometimes (25-49% of the time) (3)
- Rarely (1-24% of the time) (4)
- Never (5)

Page Break

End of Block: 6

Start of Block: 7



Q39

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as "an abnormal and excessive lack of energy".

Which of the following statements comes closest to your view about exercise and fatigue?

By exercise we mean any physical activity that lasts for at least 30 minutes, such as walking, playing basketball, dancing, bicycling, or gardening.

- Exercise makes me feel less fatigued physically, cognitively and emotionally (3)
- Exercise makes me feel more fatigued physically, cognitively and emotionally (4)
- Exercising doesn't change the amount of fatigue I experience (5)

Q36 != Exercising

- I do not exercise (6)

Page Break

Q40

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

Have you ever discussed your fatigue or fatigue-related symptoms with the doctor you see for your Parkinson's disease?

Yes (1)

No (2)

Page Break

Display This Question:

If Q40 = No



Q41

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

Why have you not previously discussed your fatigue or fatigue-related symptoms with your doctor?

Please select all that apply.

- I feel there is nothing the doctor can do about it (1)
 - I feel it's a normal part of the disease, and that talking about it won't help (2)
 - Fatigue is not as bothersome as other symptoms and I focus on the more bothersome symptoms when speaking with my doctor (3)
 - I can manage my fatigue, so I don't feel it's necessary to discuss (4)
 - Some other reason (Please specify in the box below) (5)
-

Page Break

Display This Question:

If Q40 = Yes

Q42

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

The first time you spoke about fatigue with your doctor, who initiated the conversation about your fatigue or fatigue-related symptoms?

- I brought it up with my doctor (1)
- My doctor brought it up with me (i.e., asked if I was experiencing fatigue) (2)
- My care partner brought it up (3)
- Someone else brought it up (Please specify in the box below) (4)

- I don't recall who initiated the conversation (5)

Page Break

Display This Question:

If Q40 = Yes



Q43

There are many ways in which to define fatigue. For the purpose of this survey, please think of fatigue as “an abnormal and excessive lack of energy”.

What was the outcome of your conversation about your fatigue or fatigue-related symptoms?

Please select all that apply.

- My doctor switched the medication(s) I was taking (1)
- My doctor gave me a new medication to take (4)
- We decided to make an adjustment to my sleep pattern (5)
- We decided to make a change to my diet (6)
- Another change was made (Please specify in the box below) (7)

- Based on this conversation, no changes were made to help with fatigue (8)

Page Break

Q44 Now, we just have a few more questions for clarification purposes.

Q45 Do you currently take any medication(s) for your Parkinson's Disease?

Yes (1)

No (2)

Page Break

Display This Question:

If Q45 = Yes

Q46 How many times per day do you take medication(s) for your Parkinson's disease?

For example, if you take two pills in one day at the same time, please count that as 'once a day'.
If you take 1 pill in the morning and 1 pill in the evening, please count that as '2 times a day'.

- Once a day (1)
- 2 times a day (2)
- 3 times a day (3)
- 4 times a day (4)
- 5 or more times a day (5)

Page Break

End of Block: 7

Start of Block: Modified Fatigue Impact Scale

Q47 Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. But people who have medical conditions like PD experience stronger feelings of fatigue more often and with greater impact than others.

Following is a list of statements that describe the effects of fatigue. Please read each statement carefully, then select the option that best indicates how often fatigue has affected you in this way during the past 4 weeks. Please answer every question. If you are not sure which answer to select choose the one answer that comes closest to describing you.

Because of my fatigue during the past 4 weeks

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Almost Always (5)
I have been less alert. (1)	<input type="radio"/>				
I have had difficulty paying attention for long periods of time. (2)	<input type="radio"/>				
I have been unable to think clearly. (3)	<input type="radio"/>				
I have been clumsy and uncoordinated. (4)	<input type="radio"/>				
I have been forgetful. (5)	<input type="radio"/>				
I have had to pace myself in my physical activities. (6)	<input type="radio"/>				
I have been less motivated to do anything that requires physical effort. (7)	<input type="radio"/>				

I have been less motivated to participate in social activities. (8)

I have been limited in my ability to do things away from home. (9)

I have trouble maintaining physical effort for long periods. (10)

I have had difficulty making decisions. (11)

I have been less motivated to do anything that requires thinking. (12)

My muscles have felt weak. (13)

I have been physically uncomfortable. (14)

I have had trouble finishing tasks that require thinking. (15)

I have had difficulty organizing my thoughts when doing things at home or at work. (16)

I have been less able to complete tasks that require physical effort. (17)

My thinking has been slowed down. (18)

I have had trouble concentrating. (19)

I have limited my physical activities. (20)

I have needed to rest more often or for longer periods. (21)

Page Break

End of Block: Modified Fatigue Impact Scale
