Parkinson’s Well-Being Map™
Supporting communication of my Parkinson’s
**Introduction**

**Parkinson’s disease** is a progressive, chronic neurodegenerative disease. The prevalence in industrialized nations is estimated at 1 in 100 people over the age of 60\(^1\) and is rarer in people under 50 years of age. It is predominantly characterized by problems with body movements, known as ‘motor symptoms’ – the most recognizable being tremor. However, the non-motor symptoms are missed by neurologists in 59% of consultations\(^2\) and also often undeclared by people with Parkinson’s to healthcare professionals\(^3\) resulting in under-diagnosis and under treatment.

The **Parkinson’s Well-Being Map™** has been developed to support communication of a person’s Parkinson’s status with their care team.

Using the Map you are able to:

- **Monitor your condition**
- **Review your motor and non-motor symptoms**
- **Make the most of your consultation to focus on the questions important to you**

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How to complete the Parkinson’s Well-Being Map™

The Parkinson’s Well-Being Map™ contains several copies that you and/or your partner can use to:

- Monitor symptoms over time.
- Summarize your health and well-being over the past month in preparation for your consultation.

1. Use the chart to identify and rate the frequency of your symptoms

   - Fill the date on the top of the page.
   - For each aspect of your well-being (e.g., Mood, Pain, Movement, etc. represented with different color codes), work alone or with your partner to identify the symptoms that you have experienced over the last month.
   - For each symptom identified, record its frequency in the box provided where:
     
     0 = Never    1 = Occasionally    2 = Sometimes
     3 = Often    4 = Always

2. Circle your most troublesome symptom

   For each aspect of your well-being (e.g., Mood, Pain, Movement, etc. represented with different color codes), identify and circle the most troublesome symptom for you.
How to complete the Parkinson’s Well-Being Map™ (cont.)

3 Rate the frequency of your most troublesome symptom

For each aspect of your well-being (e.g., Mood, Pain, Movement, etc. represented with different color codes), rate the frequency of the most troublesome symptom by circling the most appropriate number on the 0-4 scale where:

0 = Never  1 = Occasionally  2 = Sometimes  3 = Often  4 = Always

4 Connect up your numbers

Connect up the numbers you have selected by drawing lines between them. This will generate a pattern which will provide an instant visual record of your current well-being.

5 Other aspects of your Parkinson’s well-being

- Highlight the symptoms that are of most concern to you.
- List the three most important questions you wish to ask your care team at your next consultation.
- Medications you have taken over this period – you may want to highlight any new medications you have started since the last consultation (including over-the-counter remedies such as aspirin, etc.).
- Once completed, the Map can be taken to your next consultation to share with your care team.
Sleep disturbances
- No symptoms experienced
- I have restless sleep
- I have difficulty falling asleep at night
- I have difficulty staying asleep
- I have difficulty getting back to sleep once awake
- I have morning tiredness
- I have fatigue during the day
- I frequently doze off at inappropriate moments
- Other: ........................................

Attention/Memory
- No symptoms experienced
- I lose my train of thought during conversations
- I am unable to concentrate during activities
- I have slowness of speech
- I am forgetful
- I have difficulty remembering names, numbers, events
- Other: ........................................

Digestion and the Gut
- No symptoms experienced
- I have difficulty swallowing
- I am dribbling/drooling (a lot of saliva)
- I have bouts of vomiting or feeling sick (nausea)
- I have constipation
- I have diarrhea
- I have an upset stomach
- Other: ........................................

Movement
- No symptoms experienced
- My feet feel stuck to the floor/I have trouble starting to move
- My movements feel stiff (Rigidity) predominantly in the early morning after waking-up
- I have stiffness (Rigidity) throughout the day
- I have shaking (Tremor)
- I have slowness of movement (Bradykinesia)
- I have decreased ability to move at some times during the day
- I have involuntary movements (Dyskinesias)
- I lose my balance
- I fall over
- I lean towards or to the side
- I have trouble talking
- I have small handwriting (Micrographia)
- Other: ........................................

Bladder and Sexual Function
- No symptoms experienced
- I feel the urge to pass urine
- I get up at night to pass urine
- I have an altered interest in sex
- I have difficulty having sex
- Other: ........................................

Other Non-Motor Symptoms
- No symptoms experienced
- I feel light-headed/dizzy when standing from a lying position
- I fall due to fainting/blackouts
- I notice a change in my ability to smell/taste
- I notice a change in weight (not due to change in diet)
- I have excessive sweating
- I see/hear things that are not there
- Other: ........................................

Pain
- No symptoms experienced
- I have early morning painful cramps (dystonia) affecting toes, fingers, ankles, wrists causing me to wake up
- I have painful, stiff limbs during the day
- I have painful, stiff limbs at night
- I have shock-like shooting pain down my limbs
- I have pain with abnormal involuntary movements (Dyskinesia)
- I have severe headaches
- Other: ........................................

Mood
- No symptoms experienced
- I feel a loss of interest
- I lack pleasure from things I used to enjoy
- I feel unhappy
- I am anxious, frightened or panicky
- I am depressed
- Other: ........................................

To download additional maps go to www.parkinsons-voices.eu

To complete your Parkinson's Well-Being Map refer to steps 1-5 detailed on the previous pages.
The aspect I want to focus on the most is:

- [ ] Sleep disturbances
- [ ] Attention/Memory
- [ ] Digestion and the Gut
- [ ] Movement
- [ ] Pain
- [ ] Bladder and Sexual Function
- [ ] Other Non-Motor Symptoms
- [ ] Moods

The three most important questions to ask my care team are:

1. .............................................................. .............................................................. ..............................................................
2. .............................................................. .............................................................. ..............................................................
3. .............................................................. .............................................................. ..............................................................

Did I have time to ask all my questions?

- [ ] Yes
- [ ] No

Parkinson’s Medication below are suggested

I am taking the following Parkinson’s Medications:

- [ ] Levodopa + carbidopa/Parcopa *
- [ ] Levodopa + carbidopa/Sinemet *
- [ ] Levodopa + carbidopa/ Sinemet CR *
- [ ] Levodopa + carbidopa + entacapone/Stalevo *
- [ ] Bromocriptine/Parlodel *
- [ ] Pramipexole dihydrochloride/Mirapex *
- [ ] Pramipexole dihydrochloride/Mirapex ER *
- [ ] Ropinirole hydrochloride/Requip *
- [ ] Ropinirole hydrochloride/Requip XL *
- [ ] Rotigotine/Neupro *
- [ ] Apomorphine hydrochloride/Apokyn *
- [ ] Rasagiline mesylate/Azilect *
- [ ] Selegiline hydrochloride/Eldepryl *
- [ ] Selegiline hydrochloride/Zelapar *

- [ ] Entacapone/Comtan *
- [ ] Tolcapone/Tasmar *
- [ ] Amantadine hydrochloride
- [ ] Trihexyphenidyl hydrochloride
- [ ] Benztrapine mesylate/Cogentin *

Sources:
4) http://dailymed.nlm.nih.gov/dailymed/about.cfm

Over-the-counter medication (e.g., aspirin)

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