

Parkinson's Well-Being Map™

Supporting communication of my Parkinson's

Developed by UCB. Parkinson's Well-Being Map™ is a trademark of the UCB Group of Companies.
©2013 UCB, Inc. Smyrna, GA 30080. All rights reserved.

CNS-OTH-023868-072013
RTG-PRM-026993-1013

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 60¹ 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 consultations² and also often undeclared by people with Parkinson's to healthcare professionals³ resulting in under-diagnosis and under treatment.

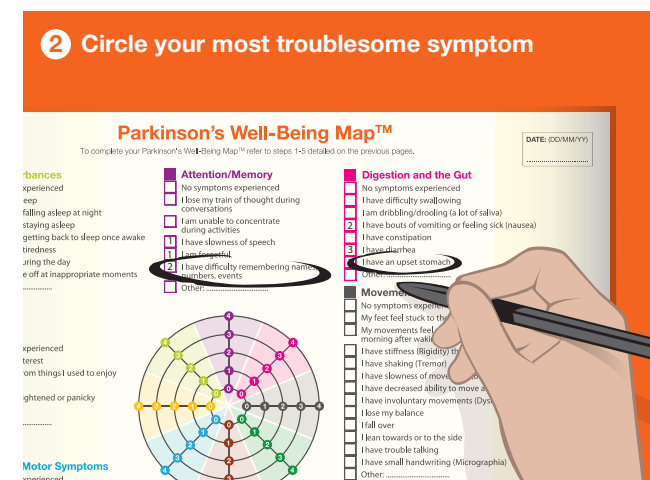
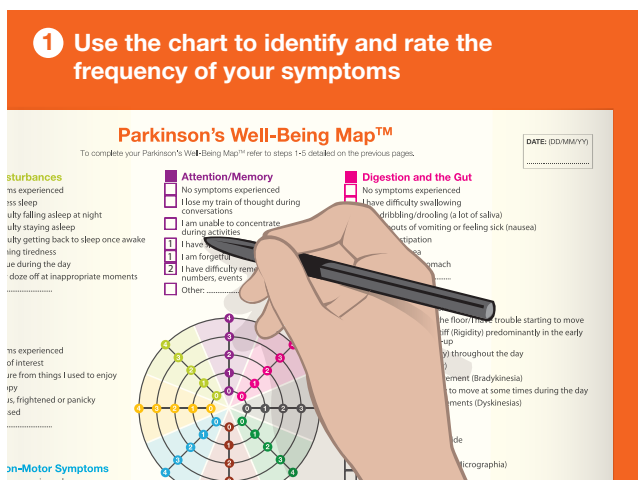
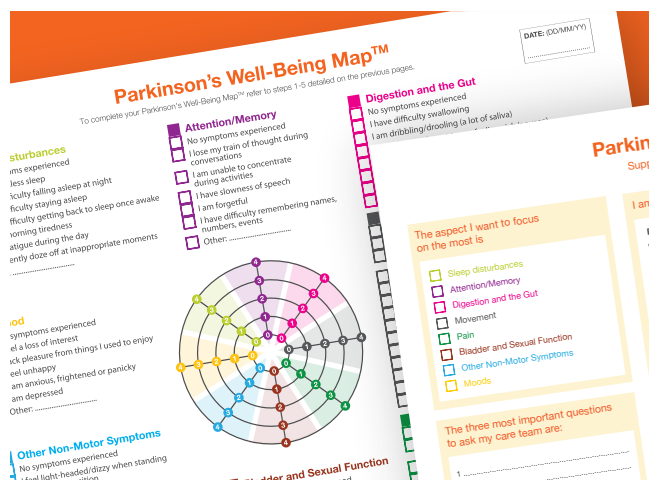
The **Parkinson's Well-Being Map™** has been developed to support communication of a person's Parkinson's status with their care team.

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**

1. de Lau LM, Breteler MM. Epidemiology of Parkinson's disease. *Lancet Neurol*. 2006 Jun;**5**(6):525-35.
2. Shulman LM *et al*. *Parkinsonism Relat Disord* 2002;**8**(3):193–197
3. Clarke CE *et al*. *Br J Clin Pract* 1995;**49**(6):288–293

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.

- 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

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

Parkinson's Well-Being Map™
To complete your Parkinson's Well-Being Map™ refer to steps 1-5 detailed on the previous pages. DATE: (DD/MM/YY)

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

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 diarrhoea
- I have an upset stomach
- Other: _____

Movement

- No symptoms experienced
- My feet have trouble starting to move
- My feet feel stuck to the floor (predominantly in the early morning)
- I have trouble starting to move
- My movements are slow (predominantly in the early morning)
- I feel stiff during the day
- I have tremor during the day
- I have tremor at night
- I have tremor when standing
- I have tremor when sitting
- I have tremor when driving
- I have tremor when eating
- I have tremor when talking
- I have tremor when writing
- I have tremor when using tools
- I have tremor when using a computer
- I have tremor when using a mobile phone
- I have tremor when using a television
- I have tremor when using a radio
- I have tremor when using a microwave
- I have tremor when using a washing machine
- I have tremor when using a dryer
- I have tremor when using a vacuum cleaner
- I have tremor when using a lawnmower
- I have tremor when using a garden hose
- I have tremor when using a power drill
- I have tremor when using a hammer
- I have tremor when using a saw
- I have tremor when using a shovel
- I have tremor when using a pitchfork
- I have tremor when using a knife
- I have tremor when using a fork
- I have tremor when using a spoon
- I have tremor when using a glass
- I have tremor when using a cup
- I have tremor when using a plate
- I have tremor when using a bowl
- I have tremor when using a can
- I have tremor when using a jar
- I have tremor when using a lid
- I have tremor when using a knob
- I have tremor when using a handle
- I have tremor when using a wheel
- I have tremor when using a pedal
- I have tremor when using a lever
- I have tremor when using a button
- I have tremor when using a switch
- I have tremor when using a dial
- I have tremor when using a knob
- I have tremor when using a handle
- I have tremor when using a wheel
- I have tremor when using a pedal
- I have tremor when using a lever
- I have tremor when using a button
- I have tremor when using a switch
- I have tremor when using a dial

Motor Symptoms

- No symptoms experienced
- I have aches and pains
- I have stiffness
- I have difficulty walking
- I have difficulty standing
- I have difficulty sitting
- I have difficulty lying down
- I have difficulty getting up
- I have difficulty getting dressed
- I have difficulty getting into a car
- I have difficulty getting out of a car
- I have difficulty getting into a house
- I have difficulty getting out of a house
- I have difficulty getting into a room
- I have difficulty getting out of a room
- I have difficulty getting into a bathroom
- I have difficulty getting out of a bathroom
- I have difficulty getting into a kitchen
- I have difficulty getting out of a kitchen
- I have difficulty getting into a bedroom
- I have difficulty getting out of a bedroom
- I have difficulty getting into a living room
- I have difficulty getting out of a living room
- I have difficulty getting into a dining room
- I have difficulty getting out of a dining room
- I have difficulty getting into a hallway
- I have difficulty getting out of a hallway
- I have difficulty getting into a staircase
- I have difficulty getting out of a staircase
- I have difficulty getting into a lift
- I have difficulty getting out of a lift
- I have difficulty getting into a car
- I have difficulty getting out of a car
- I have difficulty getting into a house
- I have difficulty getting out of a house
- I have difficulty getting into a room
- I have difficulty getting out of a room
- I have difficulty getting into a bathroom
- I have difficulty getting out of a bathroom
- I have difficulty getting into a kitchen
- I have difficulty getting out of a kitchen
- I have difficulty getting into a bedroom
- I have difficulty getting out of a bedroom
- I have difficulty getting into a living room
- I have difficulty getting out of a living room
- I have difficulty getting into a dining room
- I have difficulty getting out of a dining room
- I have difficulty getting into a hallway
- I have difficulty getting out of a hallway
- I have difficulty getting into a staircase
- I have difficulty getting out of a staircase
- I have difficulty getting into a lift
- I have difficulty getting out of a lift

4 Connect up your numbers

Parkinson's Well-Being Map™
To complete your Parkinson's Well-Being Map™ refer to steps 1-5 detailed on the previous pages. DATE: (DD/MM/YY)

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

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 diarrhoea
- I have an upset stomach
- Other: _____

Movement

- No symptoms experienced
- My feet have trouble starting to move
- My feet feel stuck to the floor (predominantly in the early morning)
- I have trouble starting to move
- My movements are slow (predominantly in the early morning)
- I feel stiff during the day
- I have tremor during the day
- I have tremor at night
- I have tremor when standing
- I have tremor when sitting
- I have tremor when driving
- I have tremor when eating
- I have tremor when talking
- I have tremor when writing
- I have tremor when using tools
- I have tremor when using a computer
- I have tremor when using a mobile phone
- I have tremor when using a television
- I have tremor when using a radio
- I have tremor when using a microwave
- I have tremor when using a washing machine
- I have tremor when using a dryer
- I have tremor when using a vacuum cleaner
- I have tremor when using a lawnmower
- I have tremor when using a garden hose
- I have tremor when using a power drill
- I have tremor when using a hammer
- I have tremor when using a saw
- I have tremor when using a shovel
- I have tremor when using a pitchfork
- I have tremor when using a knife
- I have tremor when using a fork
- I have tremor when using a spoon
- I have tremor when using a glass
- I have tremor when using a cup
- I have tremor when using a plate
- I have tremor when using a bowl
- I have tremor when using a can
- I have tremor when using a jar
- I have tremor when using a lid
- I have tremor when using a knob
- I have tremor when using a handle
- I have tremor when using a wheel
- I have tremor when using a pedal
- I have tremor when using a lever
- I have tremor when using a button
- I have tremor when using a switch
- I have tremor when using a dial

Motor Symptoms

- No symptoms experienced
- I have aches and pains
- I have stiffness
- I have difficulty walking
- I have difficulty standing
- I have difficulty sitting
- I have difficulty lying down
- I have difficulty getting up
- I have difficulty getting dressed
- I have difficulty getting into a car
- I have difficulty getting out of a car
- I have difficulty getting into a house
- I have difficulty getting out of a house
- I have difficulty getting into a room
- I have difficulty getting out of a room
- I have difficulty getting into a bathroom
- I have difficulty getting out of a bathroom
- I have difficulty getting into a kitchen
- I have difficulty getting out of a kitchen
- I have difficulty getting into a bedroom
- I have difficulty getting out of a bedroom
- I have difficulty getting into a living room
- I have difficulty getting out of a living room
- I have difficulty getting into a dining room
- I have difficulty getting out of a dining room
- I have difficulty getting into a hallway
- I have difficulty getting out of a hallway
- I have difficulty getting into a staircase
- I have difficulty getting out of a staircase
- I have difficulty getting into a lift
- I have difficulty getting out of a lift

5 Other aspects of your Parkinson's

Parkinson's Well-Being Map™
supporting communication of my Parkinson's

What to focus on

Other aspects of your Parkinson's

Parkinson's Medication below are suggested

- Levodopa - carbidopa/Parcopa
- Pramipexole - carbidopa/Requip
- Ropinirole - Requip
- Rotigotine/Neupro
- Apomorphine Hydrochloride/Apo
- Rasagiline mesylate/Azilect
- Selegiline hydrochloride/Eldepryl
- Selegiline hydrochloride/Zelapar
- Entacapone/Comtan
- Tolcapone/Tasmar
- Amantadine hydrochloride
- Levodopa - carbidopa/Parcopa
- Pramipexole - carbidopa/Requip
- Ropinirole - Requip
- Rotigotine/Neupro
- Apomorphine Hydrochloride/Apo
- Rasagiline mesylate/Azilect
- Selegiline hydrochloride/Eldepryl
- Selegiline hydrochloride/Zelapar
- Entacapone/Comtan
- Tolcapone/Tasmar
- Amantadine hydrochloride

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

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.

- 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.

Parkinson's Well-Being Map™

DATE: (DD/MM/YY)

To complete your Parkinson's Well-Being Map™ refer to steps 1-5 detailed on the previous pages.

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

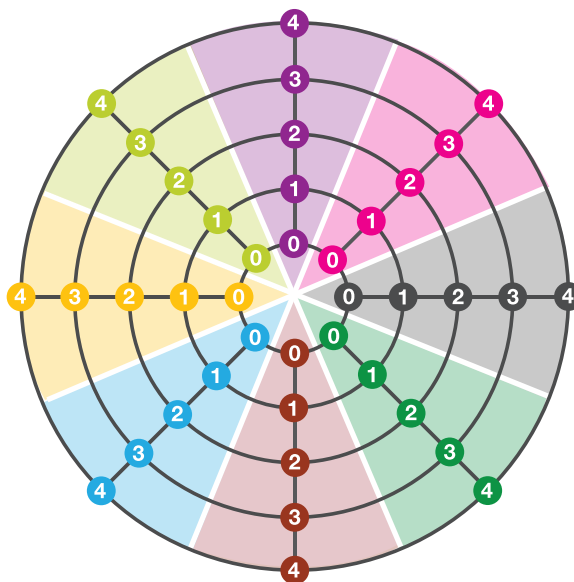
- No symptoms experienced
- I have difficulty swallowing
- I am dribbling/drooling (a lot of saliva)
- I have bouts of vomiting or feeling sick (nausea)
- I have constipation
- I have diarrhea
- I have an upset stomach
- Other:

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:

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:



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:

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:

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:

Parkinson's Well-Being Map™

Supporting communication of my Parkinson's

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:

- | | |
|---|--|
| <input type="checkbox"/> Levodopa + carbidopa/Parcopa® | <input type="checkbox"/> Entacapone/Comtan® |
| <input type="checkbox"/> Levodopa + carbidopa/Sinemet® | <input type="checkbox"/> Tolcapone/Tasmar® |
| <input type="checkbox"/> Levodopa + carbidopa/ Sinemet CR® | <input type="checkbox"/> Amantadine hydrochloride |
| <input type="checkbox"/> Levodopa + carbidopa + entacapone/Stalevo® | <input type="checkbox"/> Trihexyphenidyl hydrochloride |
| <input type="checkbox"/> Bromocriptine/Parlodel® | <input type="checkbox"/> Bzotropine mesylate/Cogentin® |
| <input type="checkbox"/> Pramipexole dihydrochloride/Mirapex® | |
| <input type="checkbox"/> Pramipexole dihydrochloride/Mirapex ER® | |
| <input type="checkbox"/> Ropinirole hydrochloride/Requip® | |
| <input type="checkbox"/> Ropinirole hydrochloride/Requip XL® | |
| <input type="checkbox"/> Rotigotine/Neupro® | |
| <input type="checkbox"/> Apomorphine hydrochloride/Apokyn® | |
| <input type="checkbox"/> Rasagiline mesylate/Azilect® | |
| <input type="checkbox"/> Selegiline hydrochloride/Eldepryl® | |
| <input type="checkbox"/> Selegiline hydrochloride/Zelapar® | |

Sources:

- 1) Summary of the recommendations of the EFNS/MDS-ES review on therapeutic management of Parkinson's disease (2013): <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-1331.2012.03866.x/full>
- 2) Drugs@FDA: FDA-approved Drug Products: http://www.accessdata.fda.gov/scripts/cder/drugsatfda/index.cfm?fuseaction=Search.Search_Drug_Name
- 3) Parkinson's disease Medications: <http://www.drugs.com/condition/parkinson-s-disease.html>
- 4) <http://dailymed.nlm.nih.gov/dailymed/about.cfm>

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

.....

.....

.....

.....

Parkinson's Well-Being Map™

Supporting communication of my Parkinson's

Contact Information

UCB Medical Information, 1950 Lake Park Drive, Smyrna, GA, USA 30080

Web: www.ucb-usa.com

Medical Information: 1-877-822-9493



Developed by UCB. Parkinson's Well-Being Map™ is a trademark of the UCB Group of Companies.
©2013 UCB, Inc. Smyrna, GA 30080. All rights reserved.

CNS-OTH-023868-072013 DOP: August 2013
RTG-PRM-026993-1013