

Parkinson's Well-Being Map™

Supporting communication of my Parkinson's

The Parkinson's Well-Being Map™ has been endorsed by:

The Cure Parkinson's Trust



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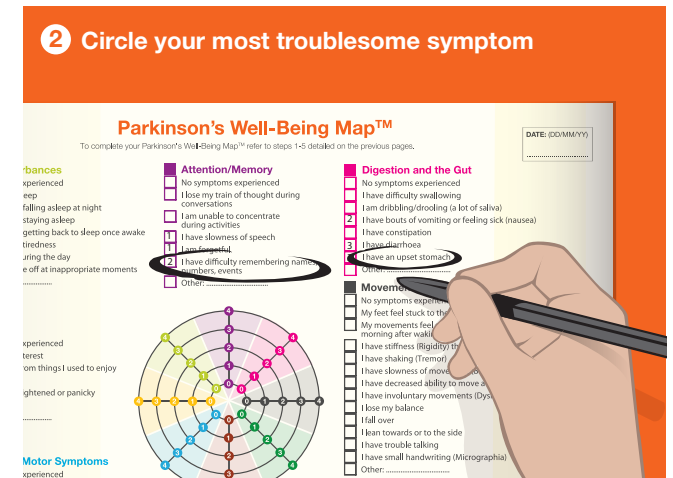
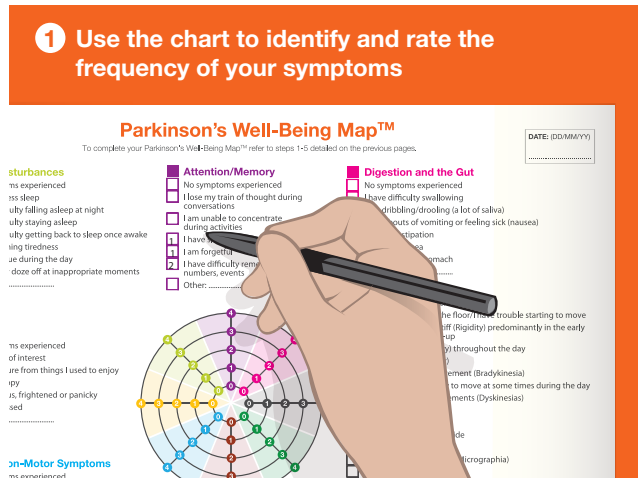
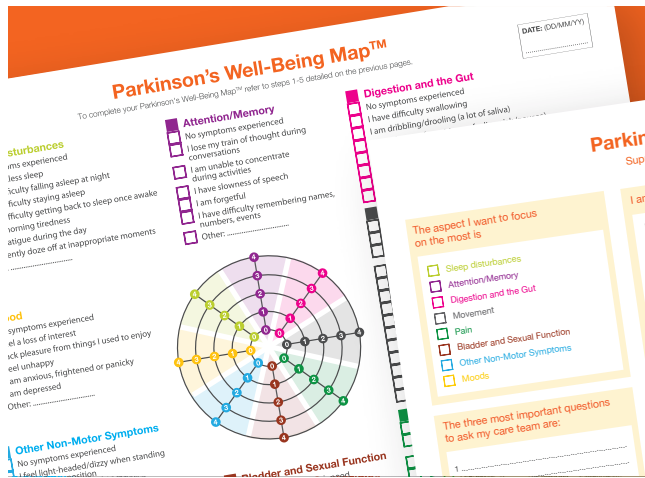
Introduction

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**

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
- Summarise 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 colour 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 colour codes), identify and circle the most troublesome symptom for you.

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

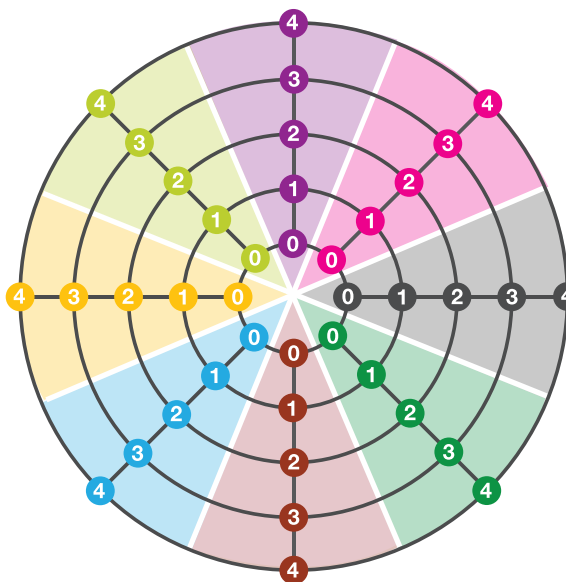
- No symptoms experienced
- I lose my train of thought during conversations
- I am unable to concentrate during activities
- I have slowness of speech
- I am forgetful
- I have difficulty remembering names, numbers, events
- Other:

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 diarrhoea
- 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:



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:

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:

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:

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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

I am taking the following medications:

- | | |
|---|--|
| <input type="checkbox"/> Levodopa + benserazide/Madopar® | <input type="checkbox"/> Ropinirole/Requip® |
| <input type="checkbox"/> Levodopa + benserazide/Madopar CR® | <input type="checkbox"/> Ropinirole/Requip XL® |
| <input type="checkbox"/> Levodopa + benserazide | <input type="checkbox"/> Ropinirole/Ipinnia XL® |
| <input type="checkbox"/> Levodopa + carbidopa/Caramet CR® | <input type="checkbox"/> Ropinirole/Ralnea XL® |
| <input type="checkbox"/> Levodopa + carbidopa/Duodopa® | <input type="checkbox"/> Ropinirole/Repinex XL® |
| <input type="checkbox"/> Levodopa + carbidopa/Sinemet® | <input type="checkbox"/> Ropinirole/Ropilynz XL® |
| <input type="checkbox"/> Levodopa + carbidopa/Sinemet CR® | <input type="checkbox"/> Ropinirole/Ropiqua PR® |
| <input type="checkbox"/> Levodopa + carbidopa/Half Sinemet® | <input type="checkbox"/> Rotigotine/Neupro® |
| <input type="checkbox"/> Levodopa + carbidopa/Sinemet® plus | <input type="checkbox"/> Apomorphine/APO-go PEN® |
| <input type="checkbox"/> Levodopa + carbidopa + entacapone/Stalevo® | <input type="checkbox"/> Apomorphine/APO-go PFS® |
| <input type="checkbox"/> Levodopa + carbidopa/Lecado® MR | <input type="checkbox"/> Apomorphine/Dacepton® |
| <input type="checkbox"/> Levodopa + carbidopa/Apodespan® PR tablets | <input type="checkbox"/> Rasagiline |
| <input type="checkbox"/> Levodopa + carbidopa/Sastravi® | <input type="checkbox"/> Rasagiline/Azilect® |
| <input type="checkbox"/> Bromocriptine | <input type="checkbox"/> Selegiline |
| <input type="checkbox"/> Bromocriptine/Parlodel® | <input type="checkbox"/> Selegiline/Eldepryl® |
| <input type="checkbox"/> Cabergoline | <input type="checkbox"/> Selegiline/Zelapar® |
| <input type="checkbox"/> Cabergoline/Cabaser® | <input type="checkbox"/> Entacapone/Comtess® |
| <input type="checkbox"/> Pergolide | <input type="checkbox"/> Opicapone/Ogentys® |
| <input type="checkbox"/> Pergolide/Celance® | <input type="checkbox"/> Tolcapone/Tasmar® |
| <input type="checkbox"/> Pramipexole | <input type="checkbox"/> Amantadine |
| <input type="checkbox"/> Pramipexole/Mirapexin® | <input type="checkbox"/> Safinamide/Xadago® |
| <input type="checkbox"/> Pramipexole/Mirapexin PR® | <input type="checkbox"/> Orphenadrine |
| <input type="checkbox"/> Pramipexole/Oprymea® | <input type="checkbox"/> Procyclidine/Kemadrin® |
| <input type="checkbox"/> Pramipexole/Oprymea® prolonged release tablets | <input type="checkbox"/> Trihexyphenidyl (benzhexol) |

Source: <https://www.parkinsons.org.uk/information-and-support/drug-treatments>

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

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

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The Cure Parkinson's Trust (CPT)

The Cure Parkinson's Trust (CPT) was set up in 2005 by four people living with the condition. It has one bold aim – to cure Parkinson's. CPT funds innovative projects and inspirational scientists with the aim of building momentum towards a cure. We bring scientists together to improve communication and promote collaboration. We adopt a direct and 'no nonsense' approach to making an impact in the research arena. As our policies are shaped by people living with Parkinson's, there is a refreshing passion and urgency in everything we do.

The Cure Parkinson's Trust

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www.cureparkinsons.org.uk

Registered charity number: 1111816

The European Parkinson's Disease Association (EPDA)

The European Parkinson's Disease Association (EPDA) is the only European umbrella organisation for Parkinson's disease. A non-political, non-religious, and non-profit making organisation, it represents 45 member organisations and is the advocate for the rights and needs of over 1.2 million people with Parkinson's and their families. EPDA's vision is to enable a full life with Parkinson's whilst supporting the search for a cure and seeks to achieve this by raising awareness and reducing inequalities in the treatment and management of Parkinson's disease across Europe.



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The Spanish Parkinson's Federation

The Spanish Federation of Parkinson Disease (FEP) was established in November 1996. It is currently composed of 45 associations spread throughout Spain which represent more than 11,500 associates. Our main objective is to improve the quality of life of patients and their families. To accomplish this, the FEP has projects related with research, training and information, free time, environment and nature, rehabilitation, or family support, among others. In the end, all projects developed improve the lives of those affected either by the training of caregivers, by promoting research or by providing rehabilitation for those affected such as physiotherapy, speech therapy, occupational therapy, psychological care, etc. which offers those affected the tools to reduce physical and psychological impact produced by the disease.

The Spanish Federation of Parkinson's disease counts on the support and advice of a scientific committee composed of eight doctors with a broad professional background on Parkinson's disease.



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<http://www.esparkinson.es/>

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If you get any **side effects**, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at <https://www.mhra.gov.uk/yellowcard>

By reporting side effects you can help provide more information on the safety of this medicine.

Side effects for Neupro® should also be reported to UCB Pharma Ltd:
UK: 0800 2793177
Ireland: 1800-930075

Contact Information

UCB Pharma, 208 Bath Road, Slough, Berkshire, SL1 3WE.

Web: www.ucbpharma.co.uk

UCBCares: UK - 0800 279 3177 or Ireland - 1800 93 00 75



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