

INSIGHTS, KNOWLEDGE AND EXPERIENCE

of treatment for people
with advanced Parkinson's



Results from a multi-country survey of people with Parkinson's

Collected information to help understand
the lived experience and needs of people
with Parkinson's, and to build awareness of
non-oral therapy options

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Introduction



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Parkinson's is currently the fastest growing neurodegenerative disease worldwide. In Europe there are more than 1.2 million people living with the condition, and worldwide no fewer than 10 million. The rapid increase in the number of people diagnosed under the age of 50 years is particularly worrying. According to Professor Bastiaan Bloem*, Parkinson's fulfils all the criteria to position it as a global pandemic.

Parkinson's is a neurodegenerative disorder that affects predominantly dopamine-producing (dopaminergic) neurons in a specific area of the brain called the substantia nigra. The disease causes motor symptoms (slowing of movements, tremor, limb rigidity, and gait and balance problems), but also non-motor symptoms (such as dementia, depression and sleep disturbances).

Unfortunately, there is no treatment at present that heals or slows down the progression of this devastating disease. On the one hand, we have a drug treatment that mainly fights the symptoms and, on the other hand, a non-drug (ie, paramedical) treatment that plays an important supportive role in the rehabilitation of patients.

Having lived with Parkinson's for almost seven years now, I realise just how important information is to be able to maximise quality of life and treatment outcomes. As such, initiatives such as this data collection project – initiated in 2021 by Parkinson's Europe (formerly the European Parkinson's Disease Association) in partnership with Britannia Pharmaceuticals – are very welcome.

The aim of this multi-country survey was to further understand the perceptions and knowledge that people with Parkinson's have about their condition and its treatment options, focusing on those who may be at the advanced stage. The teams also wanted to understand what information people receive about their treatments, in particular non-oral therapies and how and when this was discussed between them and their healthcare professional.

Parkinson's Europe is committed to helping people with Parkinson's receive the right information at the right time and increasing awareness of all the options available to them throughout their lives. In addition, it aims to encourage healthcare professionals to provide good quality information on the progression of Parkinson's and the treatment options available. Only by doing so will people with Parkinson's be able to make well-informed choices that best suit them and their families. By working together to achieve these aims, improvements in quality of life for people with Parkinson's, their families and caregivers will become a reality.

* <https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd181474>

Partnership

This data collection project was made possible with the financial support of our partner Britannia Pharmaceuticals Ltd, part of the STADA group. The survey results and individual data are the property of Parkinson's Europe.



Executive summary: insights, knowledge and experience of Parkinson's



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Our evolving understanding of Parkinson's

Parkinson's is a progressive neurodegenerative condition – one where particular nerve cells in the brain gradually stop working – and is thought to affect more than 10 million people worldwide. Most people who get Parkinson's are over the age of 60 years, but one in 10 are under the age of 50 years.

Parkinson's is caused by a gradual loss of the cells in the brain that produce dopamine. Dopamine is a neurotransmitter (a chemical messenger) that is involved in controlling movement and balance. As these dopamine-producing cells decline, the amount of dopamine available in the brain decreases so messages are not passed on properly, movement is no longer controlled smoothly and the typical symptoms of Parkinson's can then appear.

Everyone with Parkinson's experiences a different range of symptoms, but the most common and visible associated with the condition are tremor, muscle rigidity (stiffness), slowness of movement and a reduced sense of balance (postural instability). All symptoms

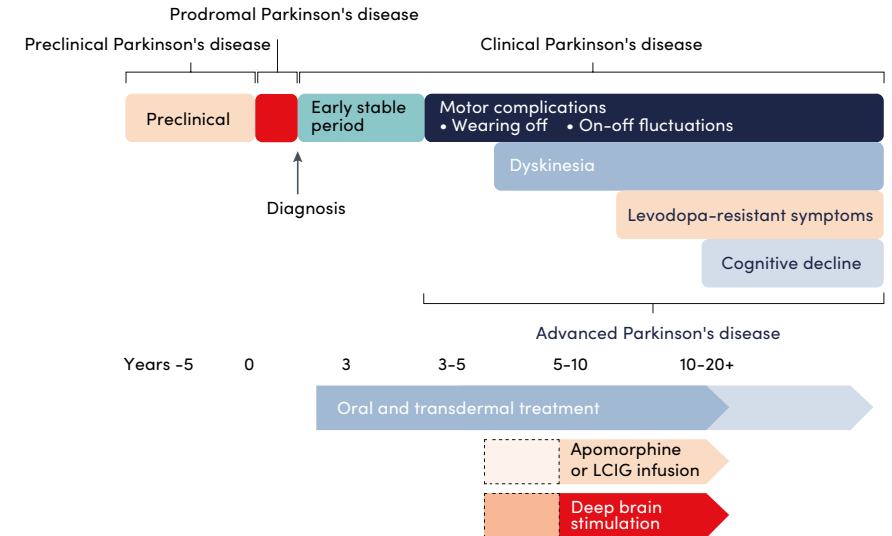
related to movement are called motor symptoms. Our understanding of Parkinson's as a condition has continued to evolve and it is now understood that it is a condition that affects more than just motor function. Non-motor symptoms, such as pain, anxiety, depression, constipation and problems thinking clearly can also be common.

The progression of Parkinson's

Parkinson's is progressive, meaning that over time symptoms will continue to worsen. However, the condition affects each person differently and so the speed of progression will also vary. Due to its progressive nature, people with Parkinson's will require ongoing support and treatment from different healthcare professionals to manage their condition for the whole of their lives. A common question people affected by Parkinson's often ask is about how their condition will progress and what this means for the future. The stages of Parkinson's can be summarised as below:

- **Before Parkinson's is diagnosed** (known as the 'prodromal' stage): Parkinson's progression is usually gradual, with symptoms slowly growing worse over time. Often people with Parkinson's believe they have probably had the condition for some time – maybe two or three years – before they received a formal diagnosis.
- **Early Parkinson's:** When Parkinson's is first diagnosed, treatment such as oral levodopa

Often it is only when symptoms become obvious or start to interfere with daily life that people visit their doctor.



Antonini A, Jenner P. Apomorphine infusion in advanced Parkinson disease. *Nat Rev Neurol.* 2018 Dec;14(12):693-694. doi: 10.1038/s41582-018-0083-y. PMID: 30279608.

is often given which can provide good control of the symptoms throughout the day. While levodopa can be effective at replacing the lost dopamine in the brain it does not stop the ongoing loss of the dopamine-producing cells and symptoms will slowly worsen over time, requiring changes or adjustments to treatment.

- **Advanced Parkinson's:** As Parkinson's continues to progress, people may find their medications are not providing as much control during the day, motor symptoms may re-emerge or they may experience involuntary movements known as dyskinesias. These are known as motor complications or fluctuations and can

“While levodopa can be effective at replacing the lost dopamine in the brain it does not stop the ongoing loss of the dopamine-producing cells”

occur for some people as early as a few years after starting levodopa therapy. The severity and unpredictability of these motor complications represents an important milestone in the progression of Parkinson's and characterises the transition to advanced Parkinson's.

The Parkinson's treatment pathway

Initial Parkinson's therapy aims to compensate for the dopamine that has been lost in the brain as nerve cells disappear. Oral levodopa, the most common initial therapy, is metabolised to dopamine in the brain. Other types of therapies, such as dopamine agonists, work by supporting the effect of dopamine in the brain. Typically, these types of therapies are given orally, which may require



multiple tablets to be taken during the day to control symptoms. As Parkinson's progresses this often results in people having to take an increasing number of tablets.

Device-aided therapies are an alternative to taking multiple oral treatments and have been developed to provide a more continuous delivery of medication, either through an infusion pump (delivering medication under the skin or directly into the intestines) or via an electrical stimulator surgically implanted in the brain (deep brain stimulation).

These therapies are generally considered once a person is at an advanced stage of the condition and their symptoms are not being well-controlled with oral tablets. As device-aided therapies do not rely on taking medication orally, they can bypass some of the common gastrointestinal issues that may impede the effectiveness of oral medications.

Survey findings

In this survey we aimed to understand the perceptions and knowledge that people with Parkinson's have about their condition and the impact of its progression, with a particular focus on those at the advanced stage. Alongside this, we wanted to understand more about the therapies that are used, particularly non-oral therapies, and the information that people receive from healthcare professionals or other sources. A total of 992 responses from 53 countries across the globe were analysed. Respondents were either a person with Parkinson's or a caregiver of a person with Parkinson's.

Responses showed that all the people with Parkinson's were receiving some form of medication for their condition. However, a total of 66% of those taking oral medications indicated that they were experiencing some form of motor fluctuation – alternating periods of good and poor motor control where medication

is not working effectively – suggesting they had progressed to a more advanced stage of the condition.

Motor fluctuations can take many forms and have a significant impact on a person's ability to undertake their normal day-to-day activities. This was highlighted in the survey that showed the range of fluctuations, both motor and non-motor, experienced which people felt interfered with their quality of life.

In addition, the quality of information that people received from their healthcare professionals around advanced Parkinson's and its treatment correlated with people's satisfaction with their therapy. This highlights the fact that the better people are informed about their condition, how it is progressing and the treatments available, then the better the outcomes can be for their quality of life.

Implications for Parkinson's care

Despite our increasing knowledge and understanding of Parkinson's and the development of new treatment approaches, the survey results show that a significant number of people with Parkinson's may be at the advanced stage but are not gaining access to, or information about, appropriate

available treatment options.

People should be encouraged to engage with their Parkinson's specialist proactively to highlight any problems they are experiencing – particularly regarding any decline in the effectiveness of their medication, so that alternative management strategies can be discussed.

Similarly, healthcare professionals should be providing good quality education on Parkinson's progression early in the course of the condition, and discussing the range of treatment options available to help manage the condition to ensure people living with Parkinson's have the best quality of life possible throughout their lives.

“People should be encouraged to engage with their Parkinson's specialist proactively”

Methodology

Survey development

Survey questions were devised by Parkinson's Europe in consultation with Britannia Pharmaceuticals. Questionnaire text was reviewed by Parkinson's Europe Board members and scientific advisers, as well by Britannia Pharmaceuticals' compliance team.

The aims of this survey were to:

- Understand the perceptions and knowledge of people with Parkinson's about their treatment options with a focus on those patients who may be at the advanced stage of the condition.
- Learn more about the therapies that are used to treat Parkinson's and, in particular, the non-oral therapies which may be appropriate for people progressing to the advanced stage of Parkinson's.

- Understand if people with Parkinson's receive timely and adequate information about non-oral therapies from healthcare professionals.

Versions of this online, self-completed questionnaire were provided in English, Dutch, French, German, Hungarian, Romanian, Slovenian and Spanish.

The survey was launched in March 2021 in English, with other languages added between May and November 2021. It was closed in January 2022.

The survey consisted of 26 questions, including six demographic questions. The approximate time to complete the survey was 15 minutes. Data was not collected on ethnicity or adherence to medication regimens.

The survey consisted of
26
questions

Methodology

Countries covered

Key countries: UK, Slovenia, Germany, Belgium, Romania and Spain (N=671).

Responses were received from **53 countries across the globe** including representation from North America, South America, Europe, Africa, Asia and Oceania (N=321).

Sample size

- Total respondents: N=1,063 (that clicked on the survey link).
- Persons with Parkinson's: N=712 (completed by themselves).
- Person caring for someone with Parkinson's: N=351 (completed on behalf of someone else).

Demographics

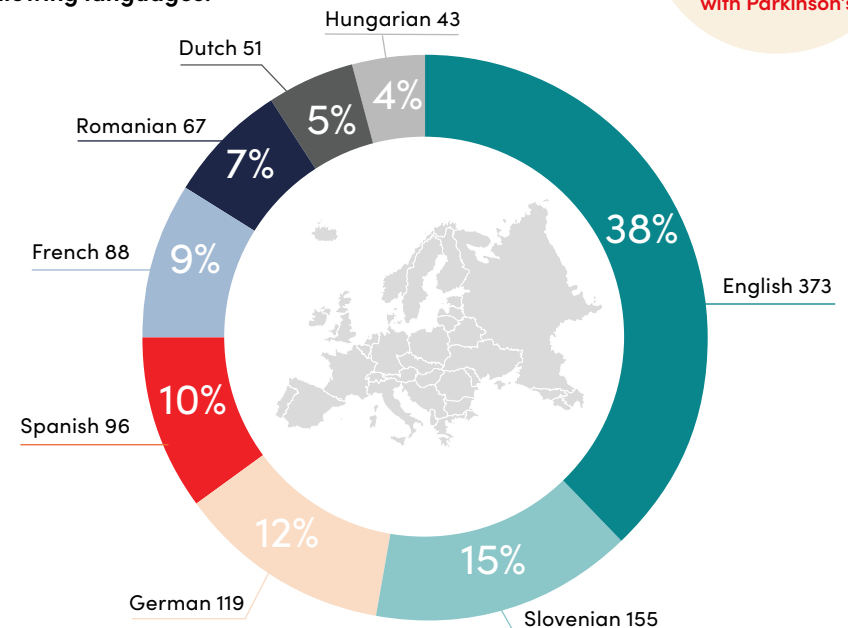
- All of the respondents are **people with Parkinson's** or completed it on behalf of someone living with Parkinson's.
- Most of the respondents were more than **55 years of age**.
- Nearly **15%** of the respondents were between the ages of **25 and 54 years**.
- Respondents were **equally distributed** between males and females.

Net response

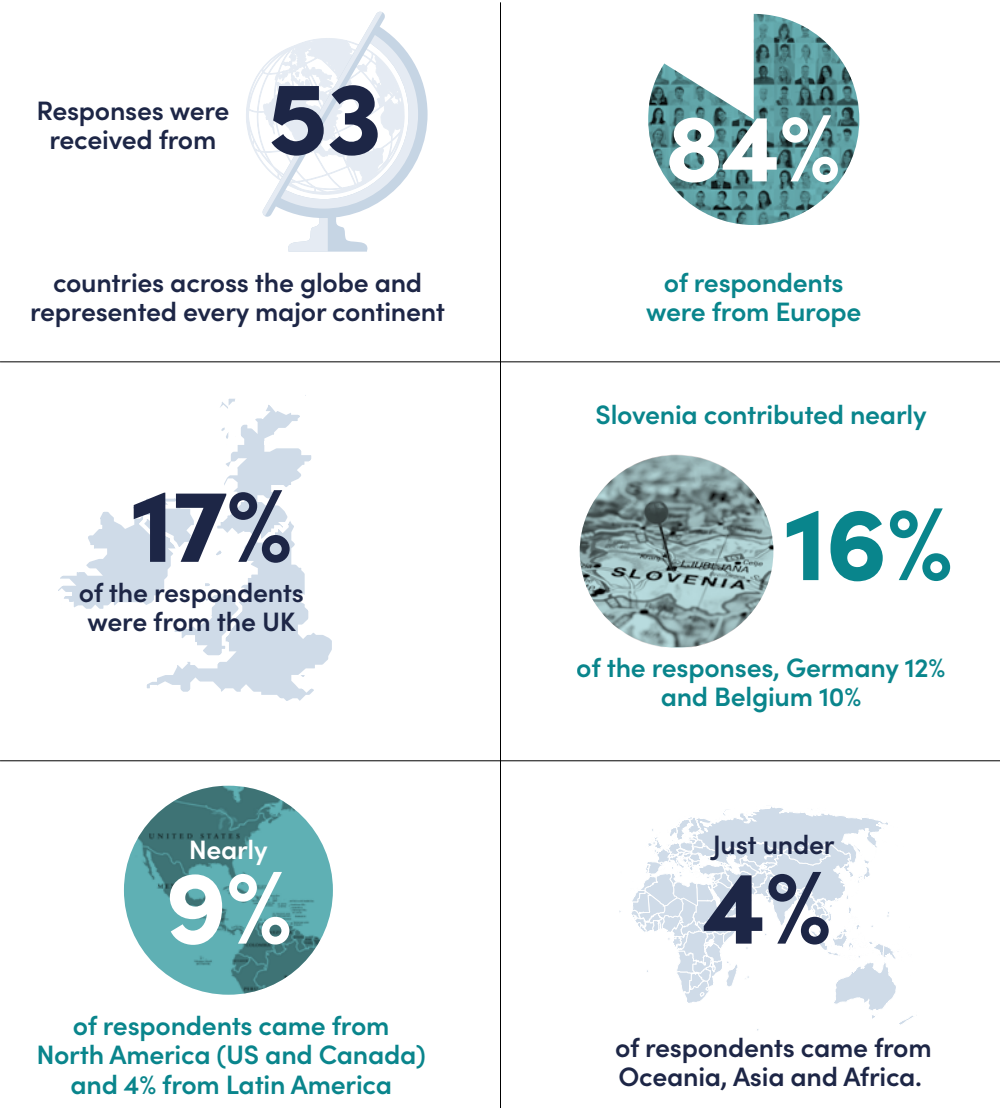
People who completed the full survey.

A total of
992
were either a person with Parkinson's or a caregiver of a person with Parkinson's

Responses received in the following languages:



Methodology:
Respondents answered the questionnaire
from all over the world – a diverse sample





Key highlights

Summary/key results 12-15

Key highlights

► Summary/key results

992 people

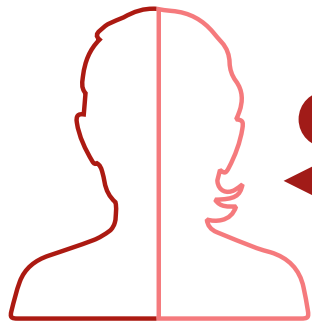
from all over the world
completed the survey

1



with **just**
under **70%**

of these being people with
Parkinson's.



MEN **WOMEN**

2

More than **80%** of those taking the
survey were **over 55 years of age** with the
respondents being **almost 50/50** between
men and women.

More than **75%** of
respondents had been living
with Parkinson's for **over four**
years with nearly **40%** having
been **diagnosed for at least**
10 years. (See pg 17.)

3

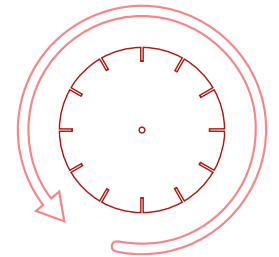


4

Over half of the respondents
indicated that, alongside living with
Parkinson's, they **had another**
long-term chronic health condition.
(See pg 18.)

Respondents indicated that the motor
symptoms that most impacted them
were issues with their **balance** and
walking, along with slowness
of movement and **rigidity**.

5



6

The most troublesome non-motor issue that
people experienced were **problems with**
their sleep. Other common issues were
problems with **memory, bowel and urinary**
problems, pain and anxiety. (See pgs 18-19.)

Almost all people with Parkinson's were being
cared for by a **specialist in Parkinson's** with
the majority having a consultation at least **1 or 2**
times per year. Just **under 40%** saw their specialist
3 or 4 times per year and **9% over 5 times per**
year. This frequency varied depending on the
location in Europe. (See pgs 20-21.)

7



Key highlights

► Summary/key results

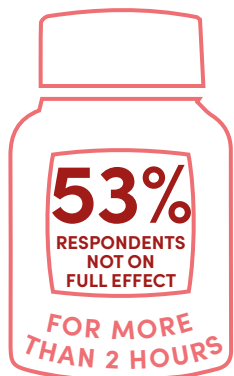
**MORE
THAN
96%**

8

More than 96% of people with Parkinson's were **taking medication** for their condition. The majority of people were taking an **oral medication**, either as a single medication or in combination with other medications. Just over **11% of people** were using a **non-oral therapy**, such as an **infusion or deep brain stimulation**. (See pg 22.)

Responses showed that people with Parkinson's were taking frequent doses of **oral medications**, with **64% taking four or more tablets/day** and **36% taking five or more tablets/day**. (See pg 23.)

9



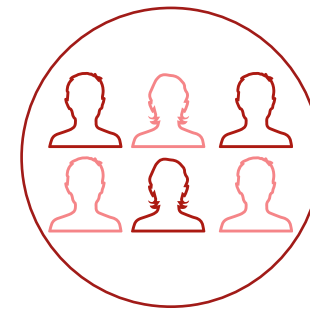
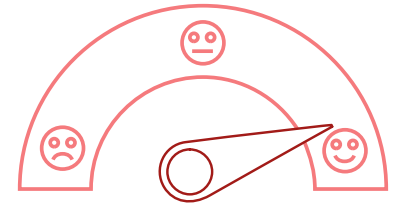
10

For people taking oral medications, **66%** reported some **variation in its effect**. The most common issues that were reported as happening '**regularly**' or '**often**' were the wearing off of the effect of a medication dose before the next one was due, a partial response (not the usual resolution of motor symptoms), or a delayed onset of effect.

In addition, **53% of respondents** reported that they were **not fully ON** (full effect of medication and control of motor function) for more than two hours of the day, which impacted their ability to carry out their normal daily activities. (See pg 24.)

Satisfaction with **oral medication** was **consistent**, both as a single treatment or when in combination with other therapies. For those receiving a **device-aided therapy** their **satisfaction with treatment was higher** than those taking oral medications alone. (See pg 25.)

11



12

More than **60% of respondents** had sought information about advanced Parkinson's, with **patient support groups** being the most common source of information. For those respondents who were directed to information sources about advanced Parkinson's, just **under half** reported this happened when they first started **oral Parkinson's treatment** and just **over 25%** when they were **discussing treatment** for advanced Parkinson's. (See pgs 28-29.)

People's **satisfaction** with their treatment was **higher** if they were satisfied with the information they received from their **neurologist** or **Parkinson's nurse**, highlighting the importance and impact of the information they receive from their healthcare professional. (See pg 30.)

13



Key results

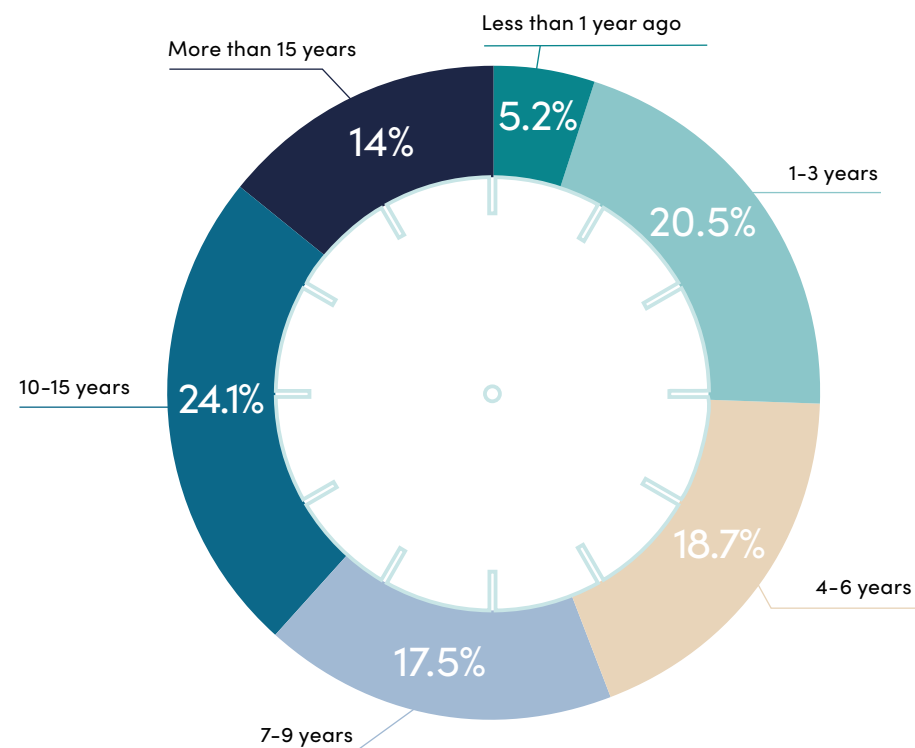
Living with Parkinson's	17-21
Parkinson's medications	22-24
Satisfaction with treatment efficacy	25
Sources of information about Parkinson's and its treatment	26-31

Results

Living with Parkinson's

How long have you been diagnosed with Parkinson's?

- Nearly 75% of the respondents had been living with Parkinson's for at least four years

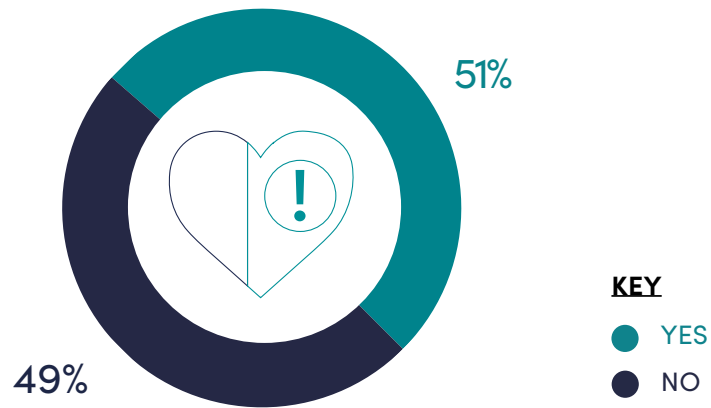


Results

Living with Parkinson's

Do you have any other health issues or chronic conditions?

- More than half of the respondents had other health issues or a chronic condition along with living with Parkinson's.



What aspect of your Parkinson's do you find most troublesome or that interferes with your quality of life?*

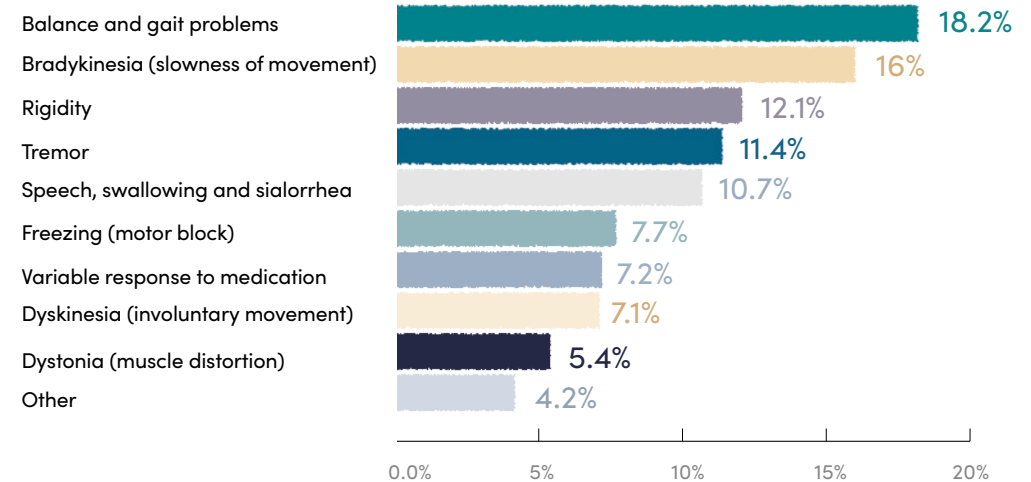
Respondents reported a range of symptoms that affected their quality of life:

- The most troublesome motor symptom that people experienced were issues with their **balance and walking (gait)**.
- People also reported issues with **slowness of their movements and rigidity**.
- The most troublesome non-motor symptom that people experienced were issues with their **sleep**.
- People also reported issues with **memory, bowel problems, urinary problems/sexual functioning, pain and anxiety**.

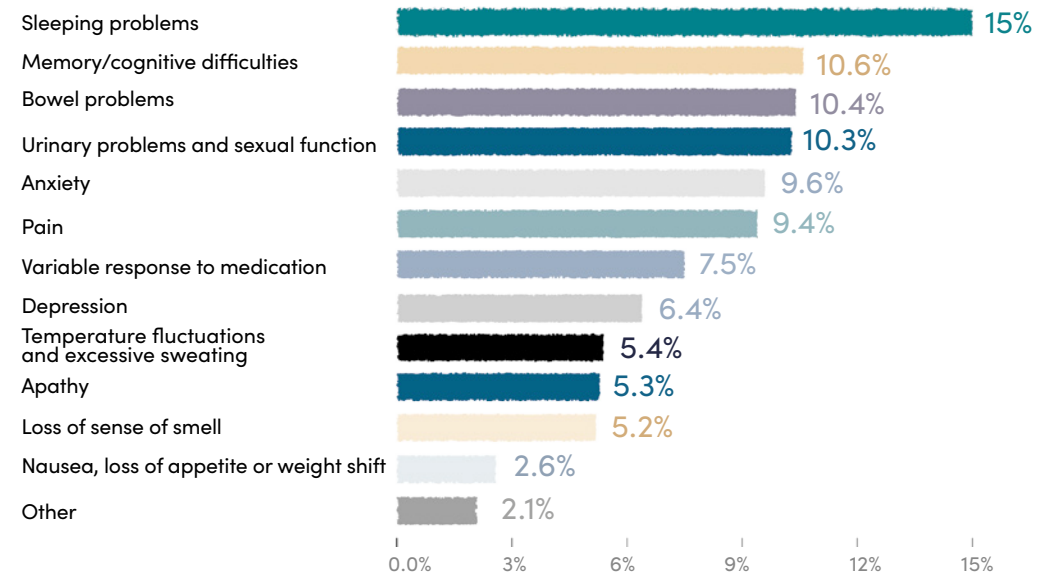
*Respondents were asked to select a maximum of three symptoms for both motor and non-motor symptoms that they found most troublesome or that interfered with their quality of life.

Results

Motor symptoms



Non-motor symptoms

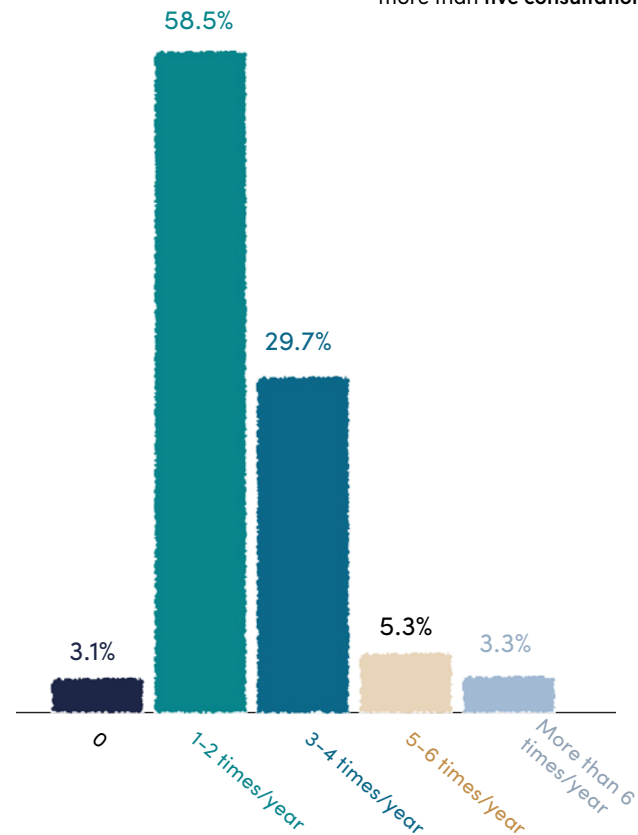


Results

Living with Parkinson's

How many times a year do you have a consultation with your neurologist or Parkinson's nurse specialist?

- Nearly every respondent was under the care of a **Parkinson's specialist**.
- Nearly **97%** of people with Parkinson's were being cared for by a specialist in Parkinson's.
- The majority of the respondents had a consultation at least **one or two times per year** with either their **neurologist or Parkinson's nurse specialist**.
- Just **under 9%** of respondents were having more than **five consultations per year**.



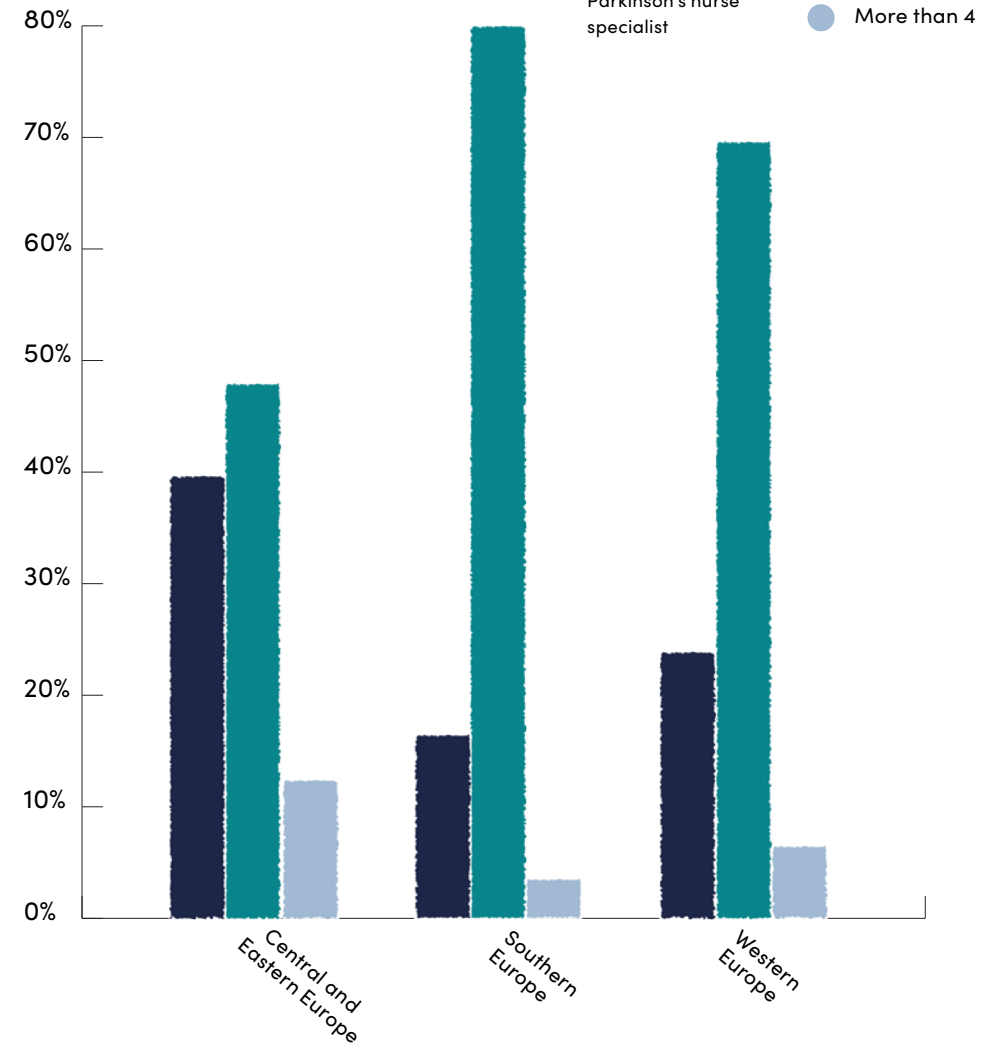
- Across Europe the frequency of how often people saw their specialist **varied significantly by region**.
- People who live in **Central, Eastern and Western Europe** regions who had 0 or 1 consultation per year was higher than for those in Southern Europe.

- People from **Southern or Western Europe** who saw their specialist 2-4 times per year was higher than for those in Central and Eastern Europe.

KEY

Number of annual consultations with neurologist or Parkinson's nurse specialist

- 0 or 1
- 2, 3 or 4
- More than 4

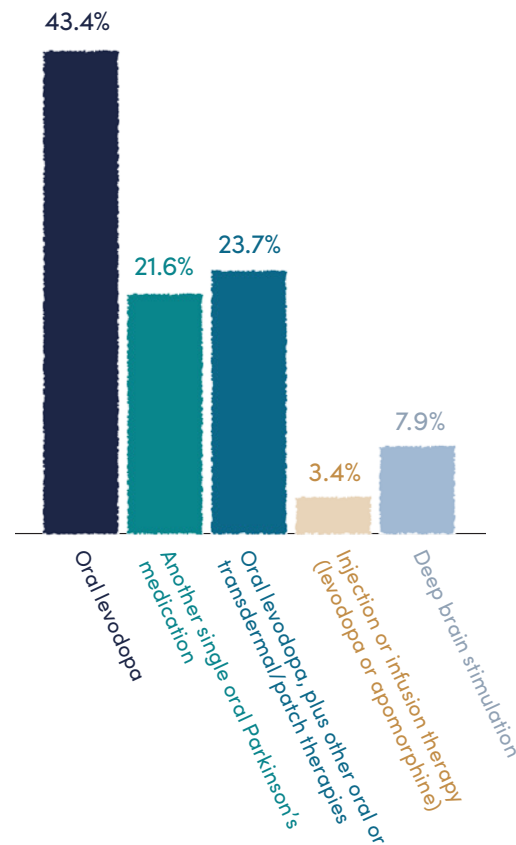


Results

Parkinson's medications

Are you currently receiving any form of medication or treatment for your Parkinson's and, if so, what type of treatment are you receiving?*

- Nearly every respondent was receiving some form of Parkinson's medication.
- More than 96% of the respondents were taking some form of medication for their Parkinson's.
- Nearly 90% of respondents were using a combination of oral and/or transdermal medications to treat their Parkinson's.
- 65% of patients were taking a single oral medication with 23% using multiple oral/transdermal medications.
- The use of non-oral therapies (injection, infusion and deep brain stimulation) was lower, with just over 11% of respondents receiving one of these therapies.
- Although the survey asked what treatment they were receiving, there was no question regarding adherence to their medication regime which is an important aspect of therapy and requires more understanding in the context of Parkinson's.



*Respondents were asked to select all the options that applied to them.

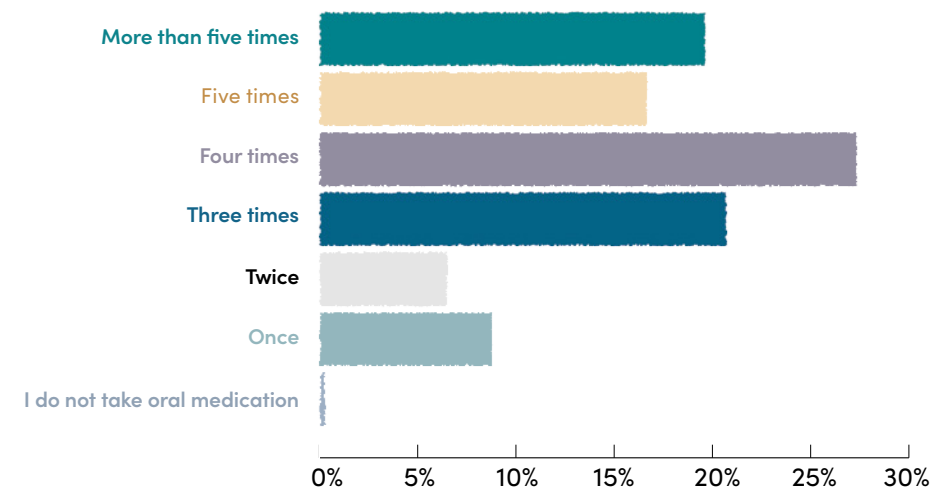
Results

Respondents were asked about their experiences with oral medications to understand the frequency of their oral medication usage and how well it controlled their Parkinson's symptoms.

They were also asked about their experiences with device-aided therapies, such as infusion therapies and deep brain stimulation.

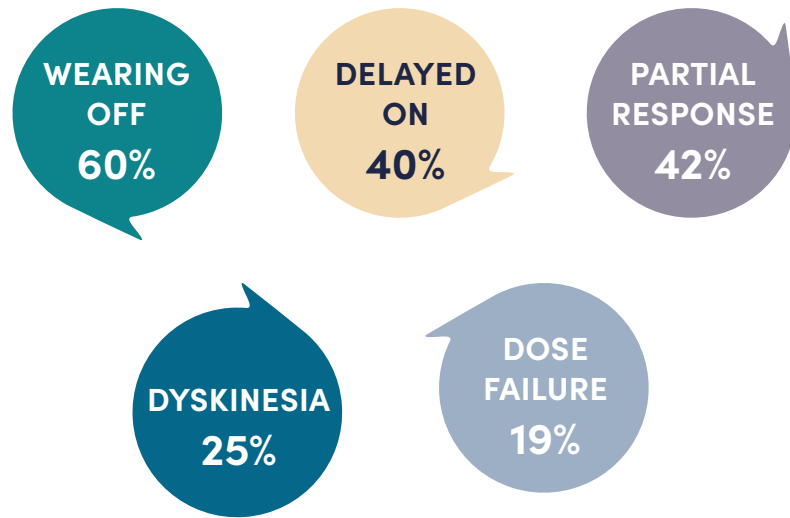
- People are often taking multiple doses of oral Parkinson's medication and report variations in its effect.
- 64% of respondents were taking four or more tablets per day, and 36% were taking more than five tablets per day.

How many times each day do you take oral Parkinson's medication (tablets?)



- Of those taking oral medications, 66% of respondents experienced variations in their effect.

Respondents who reported these variations as 'regularly' or 'often' classified these problems as:



- 53% of respondents felt that they were not fully ON for more than two hours of the day, impacting on their ability to carry out their normal daily activities.
- 28% of respondents experienced dyskinesia for more than one hour of their day.

Delayed onset of the medication, partial responses to a medication dosage and dose failures suggest that there may be gastrointestinal issues present, which are highly common in people with Parkinson's.

Results

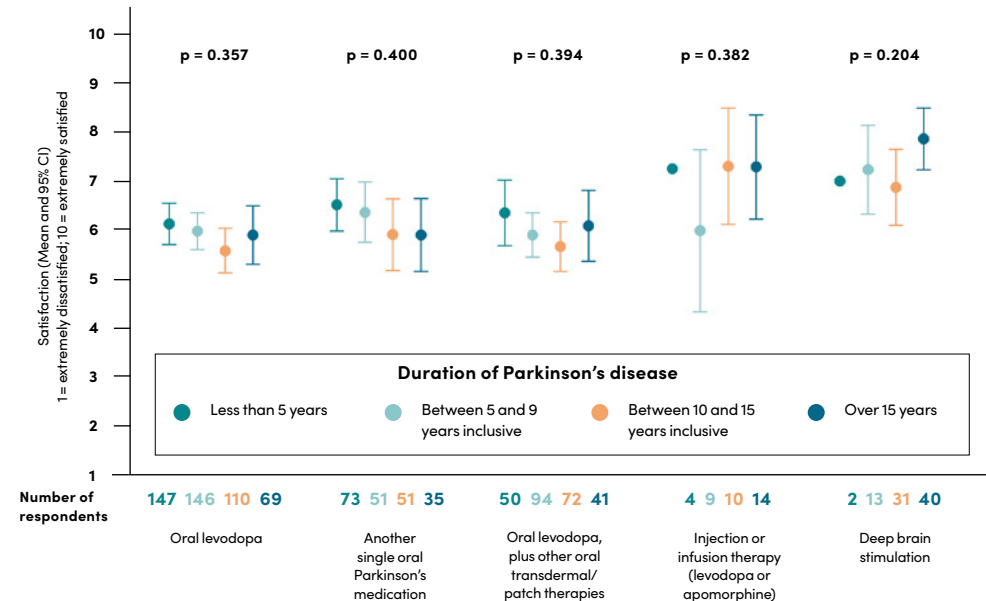
Satisfaction with treatment efficacy

On a scale of 1–10, overall, how satisfied are you that the Parkinson's treatment you are currently receiving adequately controls your symptoms? (1 = extremely dissatisfied; 10 = completely satisfied)

- As Parkinson's is a **progressive condition**, an analysis was conducted to understand how satisfaction with its treatment changed over the time that someone had been living with Parkinson's.
- Respondents' satisfaction with their oral medications was **consistent**, both as a single treatment or if they were receiving a combination of medications for their Parkinson's.
- This satisfaction with their Parkinson's treatment **did not change** depending on how long they had been living with Parkinson's.
- 12.8%** of respondents were receiving a **device-aided therapy**. Those receiving a device-aided therapy reported a higher rate of satisfaction with their treatment than those who were taking oral therapies alone.

Satisfaction with Parkinson's treatment by Parkinson's disease duration

Mean and 95% confidence interval

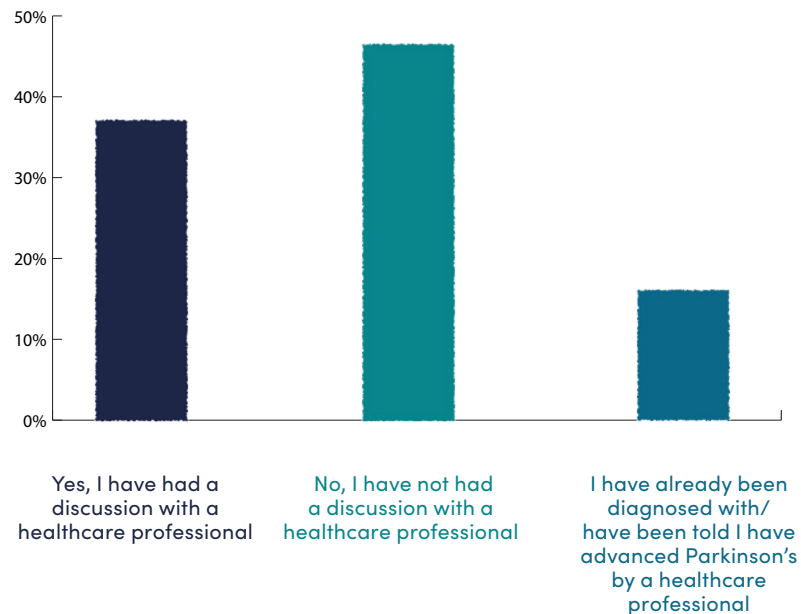


Results

Sources of information about Parkinson's and its treatment

Have you had a discussion with your neurologist, family doctor or another healthcare professional regarding disease progression and advanced Parkinson's?*

- 16% of respondents to this question had already been diagnosed with advanced Parkinson's.
- A further 37% of respondents reported that discussions of disease progression and advanced Parkinson's had already taken place with a healthcare professional.
- However, almost half (46%) had not had a discussion with a healthcare professional on these topics.

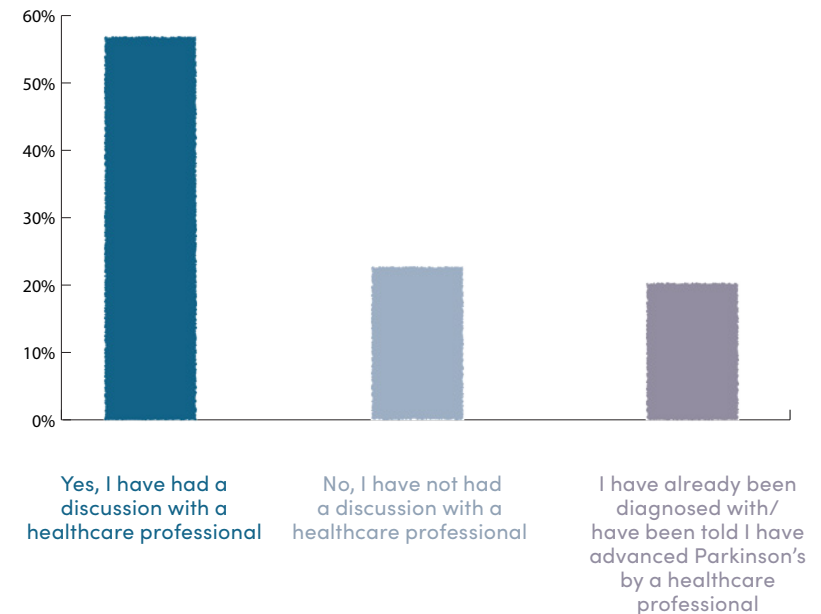


*Advanced Parkinson's' generally refers to a time when symptoms have become more complex and have a stronger effect on day-to-day life, and when non-oral therapies begin to be considered as a viable option to manage its symptoms. In the Hoehn & Yahr rating scale, advanced Parkinson's is represented by stages 4 and 5 (see www.parkinson.org/Understanding-Parkinsons/What-is-Parkinsons/Stages-of-Parkinsons).

Results

Have you had a discussion with your neurologist, family doctor or another healthcare professional about the potential treatments for advanced Parkinson's?

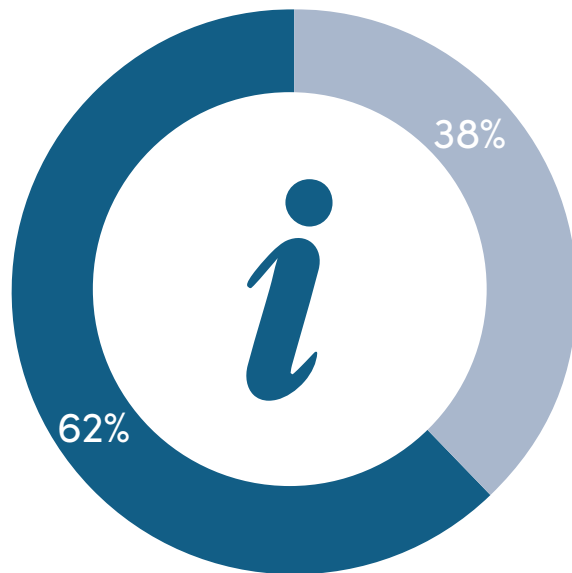
- The majority of respondents to this question had already had a discussion with a healthcare professional about potential treatments for advanced Parkinson's (57%).
- However, almost a quarter (23%) of respondents reported that they had not had a discussion with a healthcare professional about potential treatments for advanced Parkinson's.



Results

Have you sought information from any other sources about advanced Parkinson's?

- Approximately **two-thirds** of respondents had **sought further information** about advanced Parkinson's.
- More than **60%** of respondents indicated that they had sought additional information about advanced Parkinson's, highlighting the fact that people **are keen to understand** and learn more about advanced Parkinson's.



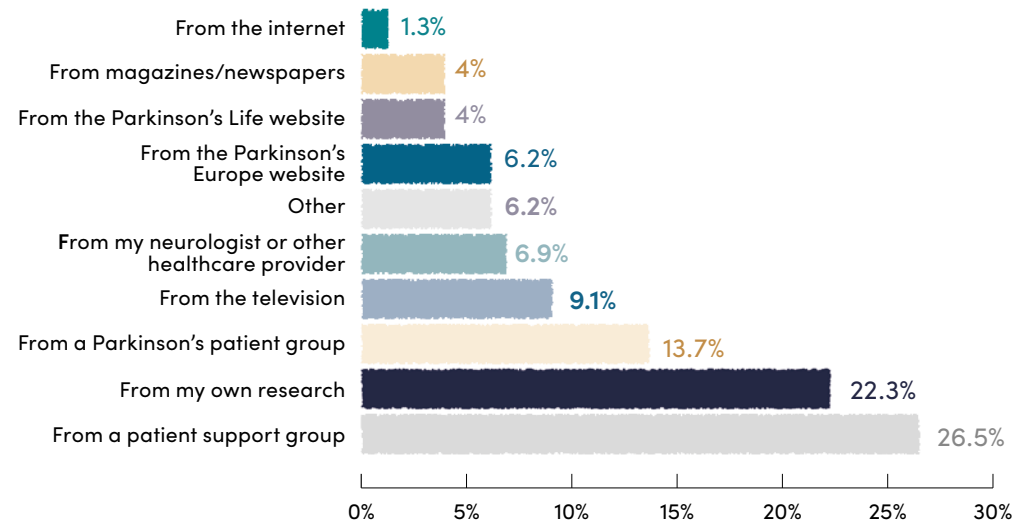
KEY

- YES. I have sought information from other sources
- NO. I haven't sought information from other sources

Results

Which other sources have you utilised?

- Respondents indicated that they **utilise** a lot of different resources to find information about advanced Parkinson's.
- The most popular sources of information are from **support groups** and **patient groups**, along with their own **research**.



If you were directed to these information sources by your neurologist or healthcare professional, when did this happen?



of respondents indicated that this was when they first started oral treatment



starting when they were discussing treatment options for advanced Parkinson's

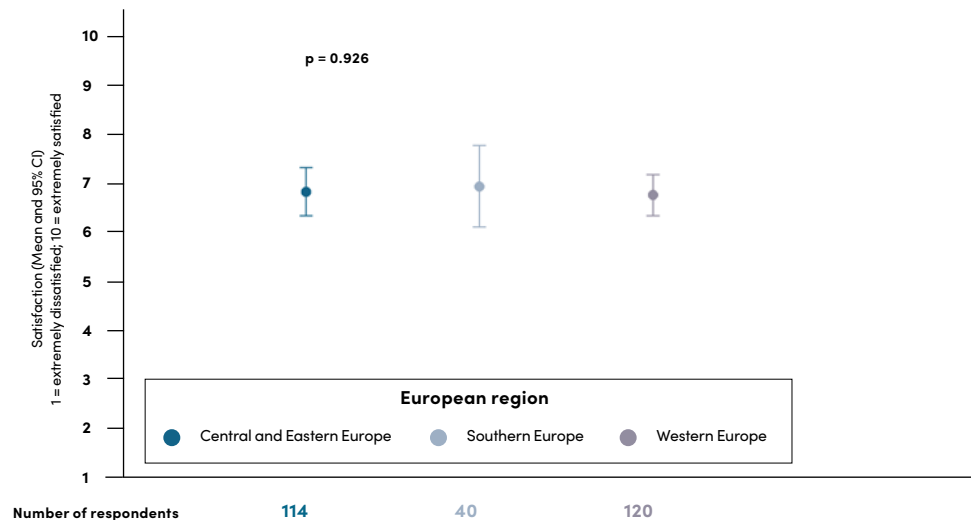
Results

How satisfied are you with the information you've received?

Overall, how satisfied are you with the information that you have received from your healthcare professional regarding treatment for advanced Parkinson's? (1 = extremely dissatisfied; 10 = completely satisfied)

- Respondents rated their satisfaction with the information they received from their healthcare professional at just **under 7**, which was consistent across all regions in Europe.

Satisfaction with information from healthcare professional regarding treatment for advanced Parkinson's
Mean and 95% confidence interval



- People with Parkinson's felt most satisfied with the treatment they were receiving if they felt a greater satisfaction with the service they received from their **neurologist or Parkinson's nurse**, highlighting the importance of the information that patients receive from their healthcare professional.
- **Education to help healthcare professionals** provide clear and supportive information to patients is important in the perception of medication benefit by the Parkinson's community.

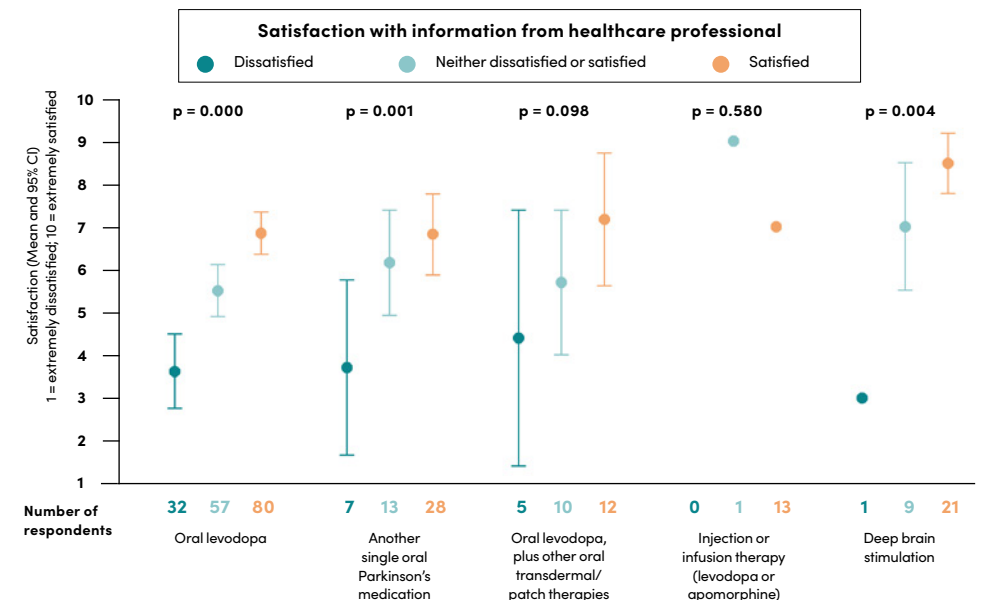
Results

How satisfied are you with the treatment you've received?

On a scale of 1–10, overall, how satisfied are you that the Parkinson's treatment you are currently receiving adequately controls your symptoms? (1 = extremely dissatisfied; 10 = completely satisfied)

- As Parkinson's is a progressive condition, an analysis was conducted to understand how satisfaction with Parkinson's treatment changed with the time that someone had been living with Parkinson's.
- Respondents' satisfaction with their oral medications was **consistent** both as a single treatment or if they were receiving a combination of medications for their Parkinson's.
- This satisfaction with their Parkinson's treatment **did not change** depending on **how long** they had been living with Parkinson's.
- **12.8%** of respondents were receiving a **device-aided therapy**. Those receiving a device-aided therapy reported a **higher rate of satisfaction** with their treatment than those who were taking oral therapies alone.

Satisfaction with information from healthcare professionals regarding treatment for advanced Parkinson's
Mean and 95% confidence interval



Recommendations



Lizzie Graham
Parkinson's Europe
Board member, UK

Parkinson's is a condition that is estimated to affect more than 10 million people globally. It has a significant impact on quality of life, not only for people living with Parkinson's but also their support network of families and caregivers. Although our understanding of the progression of Parkinson's has grown significantly, leading to improved treatment approaches to help people living with the condition, there is still much to be done to further improve the lives of people impacted by Parkinson's.

“Just under 1,000 people completed this survey from all over the globe, providing valuable insights into how Parkinson's affects their lives”

This important survey was undertaken to further understand the perceptions and knowledge that people with Parkinson's have about their condition and its treatment options, with a particular focus on those who may be at the advanced stage. This helps ensure that Parkinson's Europe can continue to work with healthcare professionals to further improve the quality of life of people living with the condition. Just under 1,000 people completed this survey from all over the globe, providing valuable insights into how Parkinson's affects their lives.

Parkinson's is a progressive neurodegenerative condition that worsens over time and

the people that responded to this survey highlighted the impact of living with this chronic condition on their daily lives. The results show that a large percentage of people with Parkinson's continue to experience both motor and non-motor fluctuations, both of which have a significant impact on their quality of life, despite the use of multiple medications. These findings suggest that some people may need to consider alternative treatment approaches to maintain a good quality of life over the long term.

There are a multitude of different treatment options available to people with Parkinson's, including both oral tablets and device-aided therapies. However, despite people seeking more information on their condition, the full range of options are not always proactively discussed with them by their healthcare professional. The survey highlighted the importance to people of, and the need for, clear and timely information from healthcare professionals about the progression of Parkinson's and the treatment options available throughout the course of the condition.

The survey results show that people with Parkinson's are seeking out their own information about advanced Parkinson's, but, importantly, feel most comfortable with their treatment if they are also satisfied with the information received from their healthcare professionals. This finding emphasises the importance of ongoing communication between healthcare professionals and people with

Parkinson's throughout their journey of living with the condition.

opportunity to help them understand their condition and the options available at the different stages.

I would strongly recommend that anybody who is experiencing a worsening of their Parkinson's symptoms and a decline in the effectiveness of their current treatment, discuss this with a member of their healthcare team. This will help them understand how their condition is progressing and the various treatment options available to help control their symptoms. Healthcare professionals should be mindful about being proactive in their discussions with people with Parkinson's, providing them with the relevant information at the earliest

“The survey highlighted the importance to people of, and the need for, clear and timely information”

Parkinson's Europe provides a wealth of information and resources to support you through your life with Parkinson's. These resources can provide valuable information and help you to become more informed so that you can work with your healthcare professionals to take control of your Parkinson's and live your best life possible.



Glossary

Akinesia: An absence of movement. A person with akinesia cannot move their muscles, even if they try.

Bradykinesia: A slowness or a difficulty of movement. It is one of the cardinal symptoms of Parkinson's.

COMT Inhibitors: A class of drug used to treat Parkinson's. They are always given in combination with levodopa as they stop the peripheral breakdown of the drug, allowing more levodopa to enter the brain where it can be converted to dopamine.

Delayed gastric emptying: A gastrointestinal problem that people living with Parkinson's can experience. Common symptoms of delayed gastric (stomach) emptying can include feeling full quickly when eating, feeling sick, loss of appetite, weight loss, bloating and abdominal pain. It may also cause problems with the absorption of oral medications.

Delayed ON: A delayed ON is when a dose of oral medication is taken and there is a delay in the medication taking effect. This is often caused by gastrointestinal problems, such as delayed gastric emptying.

Device-aided therapy (DAT): Device-aided therapies are a range of treatment options that use a medical device to treat Parkinson's. These can include:

- Infusion pumps to deliver the drug through the skin, eg, subcutaneous apomorphine
- Infusion pumps to deliver the drug directly into the intestine, eg, intrajejunal levodopa
- Deep brain stimulation

Dopamine: A neurotransmitter (chemical messenger) made in your brain. It plays a role in many body functions including movement.

Dopamine agonists: A class of drugs that are used to treat Parkinson's. Dopamine agonists, such as pramipexole and ropinirole, work by binding and stimulating the dopamine receptors in the brain.

Dyskinesia: Dyskinesia is uncontrolled, involuntary movement that may occur with long-term levodopa use and longer time with Parkinson's. Not everyone will develop this complication, and the experience of dyskinesia varies.

Levodopa: A drug used for the treatment of Parkinson's. Levodopa works by being converted to dopamine in the brain, replacing the dopamine that has been lost due to Parkinson's.

MAO-B inhibitors: A class of drug that are used to treat Parkinson's. MAO-B inhibitors, such as rasagiline, selegiline and safinamide, work by slowing the breakdown of dopamine in the brain.

ON: ON describes a time when Parkinson's medication is working, and the symptoms of Parkinson's are absent.

OFF: OFF describes a time when Parkinson's medication is not working, and the symptoms of Parkinson's are present.

Partial response: This is a type of motor fluctuation where the full effect of a dose of levodopa is not felt. This is often caused by gastrointestinal problems where the drug is not fully absorbed.

Wearing OFF: This is a type of motor fluctuation where the effect of a dose of levodopa doesn't last as long as it previously did and wears off before the next dose is taken.

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- Parkinson's Europe member organisations
www.parkinsonseurope.org/membership
- Association Antiparkinson
www.facebook.com/antiparkinsonromania
- Cure Parkinson's
www.cureparkinsons.org.uk
- European Federation of Neurological Associations
www.efna.net
- European Patients' Forum
www.eu-patient.eu
- Oruen
www.oruen.com
- touchNEUROLOGY
www.touchneurology.com
- Yuvedo Foundation
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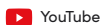
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Britannia Pharmaceuticals Ltd were involved in the design and data analysis of the original patient survey and reviewed the final report for factual accuracy, but the responsibility for the conclusions of the survey lies with Parkinson's Europe.