


The Move for Change results

Evidence from the largest European Parkinson's online patient survey reveals that people living with the disease are not getting the treatment and care they are entitled to. Find out more inside!



Information given at the time of diagnosis is not well matched to patient needs

AN INCREASED UNDERSTANDING OF PARKINSON'S AND ITS SYMPTOMS IS NECESSARY TO TREAT A PATIENT APPROPRIATELY

NEARLY 50% OF PEOPLE WITH PARKINSON'S ARE DISSATISFIED WITH THE WAY THEIR DIAGNOSIS WAS TOLD

Parkinson's diagnoses can take more than 2 years – when guidelines recommend it should take 6 weeks

ONLY 1 IN 10 PATIENTS ARE DIAGNOSED BY A PARKINSON'S SPECIALIST

European Findings



EPDA
European Parkinson's
Disease Association

The voice for Parkinson's in Europe



**ACCESS TO A
NUMBER OF
ALLIED HEALTH
SERVICES –
ESPECIALLY
PARKINSON'S
DISEASE NURSE
SPECIALISTS
– IS LIMITED
ACROSS EUROPE**

*Patient satisfaction
levels increased with
longer consultation
meetings*

**DOCTOR
CONSULTATIONS
ARE NOT BASED
ON A PATIENT'S
NEEDS**

**TRUE SHARED
DECISION MAKING
IS STILL RARE
WITH REGARDS
TO PEOPLE WITH
PARKINSON'S
TREATMENT AND
MANAGEMENT**

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WELCOME

Thank you for taking the time to read this important booklet, which reveals the key findings from the EPDA's Move for Change campaign – the largest European online patient survey on standards of care in Parkinson's to date.

The survey was designed to identify areas of care that fell short of the standards identified by the EPDA's Charter for People with Parkinson's in 1997 and current clinical guidelines. You can learn more about the survey's methods on page 8, and about the EPDA on pages 48-49.

The results of the survey have been presented in easy-to-understand infographics. This is because we believe it is essential to communicate quickly and simply the survey's core findings – that people with Parkinson's are not receiving the standards of care that disease specialists recognise as being best practice.

For further validity of our results, turn to pages 40-43 and read what two eminent Parkinson's specialists have to say. They argue that the Move for Change data can assist healthcare professionals and policymakers in improving the level of care for people with Parkinson's and their families across Europe. We agree with them. If you do too, then we would love to hear from you, and urge you to spread the word about the need for change. Our contact details are on page 49 or you can email info@epda.eu.com.



A handwritten signature in dark ink, appearing to read 'Knut-Johan Onarheim'.

Knut-Johan Onarheim
EPDA President



The full Move for Change results are available at www.epda.eu.com/move-for-change



The voice for Parkinson's in Europe

A BRIEF INTRODUCTION TO PARKINSON'S

Parkinson's is a progressive, chronic and complex neurodegenerative disease that has no cure. It affects all aspects of daily living and is the most common neurodegenerative disease after Alzheimer's. The effects of Parkinson's invariably involve the physical, cognitive and psychological domains, and impact across nearly every cultural, social and economic boundary.

Parkinson's occurs as a result of the destruction of nerve cells in the brain that produce the neurotransmitter dopamine. Due to this lack of dopamine, messages in the brain fail to transmit smoothly to the muscles, resulting in difficulties controlling movement. A similar destruction occurs naturally with ageing, but in Parkinson's the process is accelerated.

Who gets Parkinson's?

There are currently more than 1.2 million people living with Parkinson's in Europe and this number is forecast to double by 2030 primarily as a result of the ageing population. The average age of onset is 60 years, although more than one in 10 people are diagnosed before the age of 50. Parkinson's is more prevalent in men than women, and affects people of all ethnicities. It is important to remember that Parkinson's can affect anyone.

Symptoms

The severity of Parkinson's will differ from person to person as every case is different.

The disease is predominantly characterised by problems with body movements – known as motor symptoms. These symptoms include tremor, rigidity, bradykinesia and postural instability. However, Parkinson's is also associated with symptoms that are not directly related to movement – known as non-motor symptoms – which include loss of sense of smell, sleep disturbances, gastrointestinal complications, constipation, swallowing disorders, anxiety, pain, fatigue, depression, sexual dysfunction, hallucinations and psychosis, impulse control disorders, cognitive impairment and dementia.

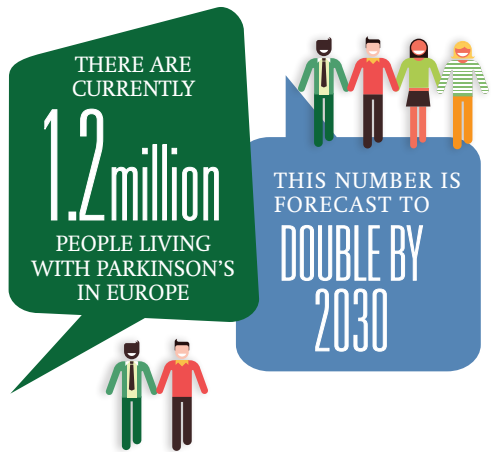
Treatment

Treatments are available for a number of aspects of Parkinson's but is not yet accessible for all. Ongoing research has resulted in significant improvements but more is needed to delay, stop or even reverse the disease. Making a true Parkinson's diagnosis is also a major challenge due to the condition's complex nature, and people who are correctly diagnosed will need medication for the rest of their lives.

“It is important to remember that Parkinson's can affect anyone”



**PARKINSON'S
HAS NO CURE**



€13.9 billion



THE ESTIMATED ANNUAL TOTAL COST OF PARKINSON'S ACROSS EUROPE. THIS FIGURE WILL INCREASE AS THE NUMBER OF PEOPLE WITH THE DISEASE CONTINUES TO GROW

After some time, however, the medication can lose its effectiveness and cause side effects that require treatment by a physician with a good knowledge of the condition. In some European countries, it is recognised that people with Parkinson's and their carers should be involved in their own disease management together with a range of healthcare professionals – known as the 'multidisciplinary team' or 'support services'. In many countries however, this is not possible.

The cost of Parkinson's

The economic consequences of Parkinson's across Europe are considerable. Studies estimate the total annual cost of the disease to be about €13.9 billion, and this figure will increase as the number of people with Parkinson's in Europe continues to grow.

Numerous studies have also shown that the annual cost of Parkinson's per person will increase as the disease becomes

more severe, while non-motor symptoms are a major source of hospitalisation and institutionalisation – both key cost-drivers in Parkinson's care.

There are also the indirect costs of the disease to consider – as a result of reduced

earnings of both the person with Parkinson's and their family carer(s), and combined with the hidden costs associated with their resulting loss of productivity.

In contrast, studies have shown that early drug treatment, together with therapeutic interventions, can reduce the economic impact of Parkinson's – and

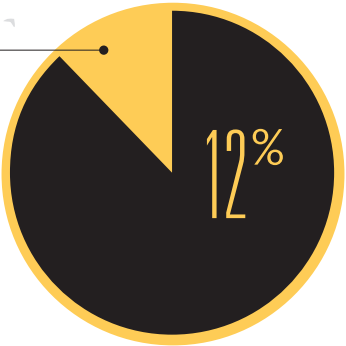
in some cases delay the progression of the disease, which maintains a person's quality of life and personal wellbeing for longer.

Other benefits that can stem from such proactive approaches include reduced hospital admissions, relapse rates and symptom severity. ■

“More is needed to delay, stop or even reverse the disease”

MOVE FOR CHANGE: THE KEY FINDINGS

ONLY A MINORITY OF
PATIENTS (12%) WERE
REFERRED TO A PARKINSON'S
SPECIALIST FOR THEIR
DIAGNOSIS *See page 12*



THE DIAGNOSIS OF THE DISEASE
CAN TAKE MORE THAN

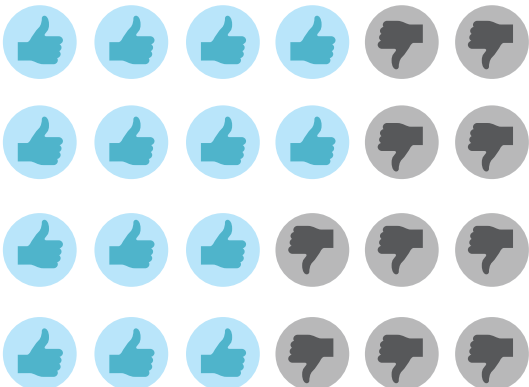
2 YEARS

DESPITE CLINICAL GUIDELINES
RECOMMENDING THAT PATIENTS
SHOULD BE REFERRED TO A
SPECIALIST FOR AN ACCURATE
DIAGNOSIS WITHIN

6 WEEKS

See page 10

NEARLY HALF OF THE RESPONDENTS WERE
DISSATISFIED WITH THE WAY THEIR
DIAGNOSIS WAS CONVEYED *See page 15*





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The information patients receive at the time of diagnosis is not well matched to their needs
See page 16



CONSULTATIONS, ALTHOUGH HELD ON A REGULAR BASIS, WERE LARGELY ROUTINE AND NOT ARRANGED BY THE PATIENT BASED ON THEIR NEEDS

See page 33



The use of the multidisciplinary team and additional support services in the treatment and care of Parkinson's has been shown to be beneficial and encouraged across Europe, but access to a number of allied health services – **such as Parkinson's disease nurse specialists – is limited**
See page 23

Although most patients felt they had been involved in decisions regarding their disease management, true shared decision making is still rare
See page 36

Continued on next page >



**PATIENT SATISFACTION
LEVELS INCREASED WITH
LONGER CONSULTATION
MEETINGS**

See page 35



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The neurologist and family doctor are the most accessible healthcare professionals, but an increased understanding of Parkinson's and its symptoms is necessary to treat a patient appropriately *See pages 25 and 27*

MOVE FOR CHANGE: THE DETAILS

BACKGROUND AND PURPOSE:

The European Parkinson's Disease Association (EPDA) launched its Charter for People with Parkinson's disease in 1997. This document – backed by the World Health Organization – outlined five basic principles that have been widely agreed to be fundamental rights for people with Parkinson's.

It states that all patients have the right to:

- be referred to a doctor with a special interest in Parkinson's
- receive an accurate diagnosis
- have access to support services
- receive continuous care
- take part in managing their illness.

The Move for Change campaign consisted of three European online patient surveys that evaluated whether these standards of care were being met.

METHODS:

The three online surveys consisted of 51 questions relating to the Charter's principles. They were available via the EPDA's website and its affiliated member associations' websites across Europe from 2010 to 2013.

NUMBERS:

5,366 questionnaires were analysed from people with Parkinson's and their carers in 35 countries.

CONCLUSIONS:

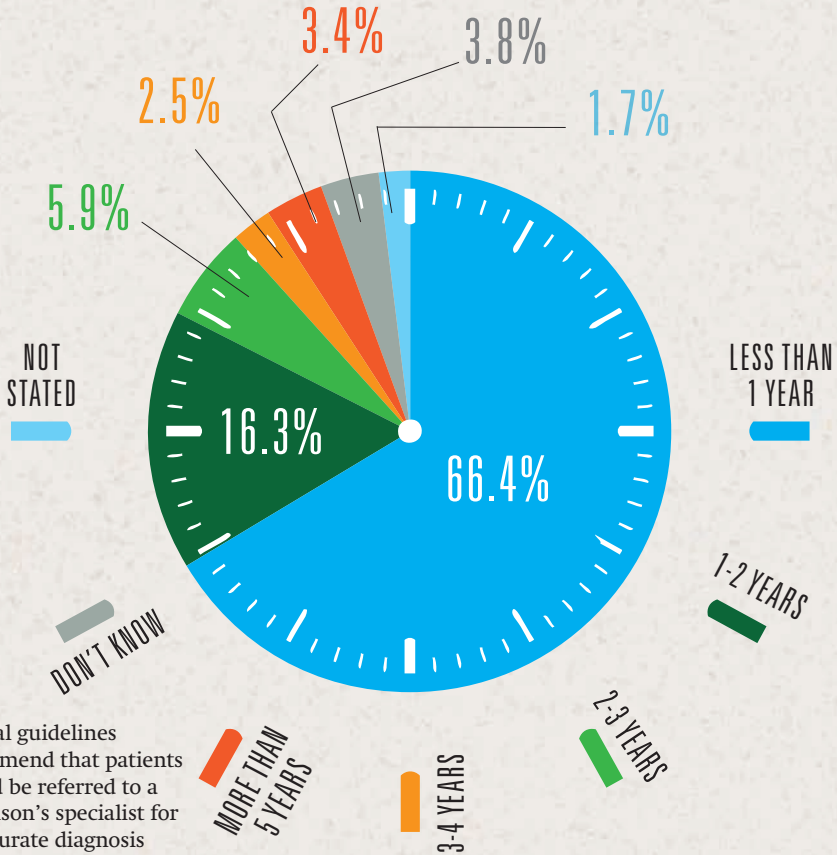
The data highlights certain challenges that people with Parkinson's still face with regards to living with their condition, despite the introduction of the EPDA's Charter in 1997 and current clinical guidelines. The findings can assist healthcare professionals and decision makers in improving the level of care for people with Parkinson's and their families across Europe.

See pages 40-43 for more detailed survey conclusions and recommendations by Professor Bastiaan Bloem and Professor Fabrizio Stocchi, two leading Parkinson's specialists.

THE MOVE FOR CHANGE RESULTS



HOW LONG DOES IT TAKE FOR A PERSON WITH PARKINSON'S TO GET DIAGNOSED?



▼ Clinical guidelines recommend that patients should be referred to a Parkinson's specialist for an accurate diagnosis within six weeks

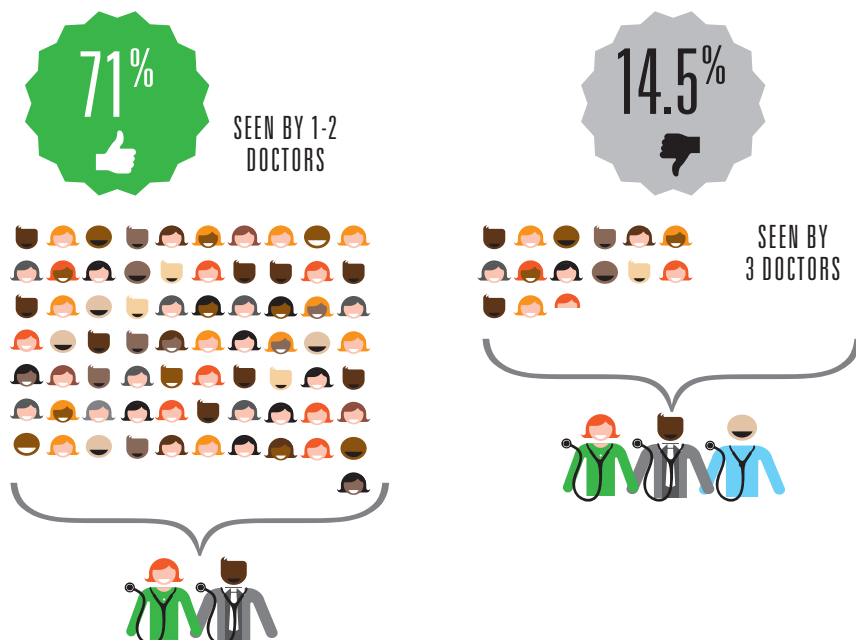
KEY FINDINGS

1 IN 3
OF THE SURVEY'S
RESPONDENTS
HAD TO WAIT

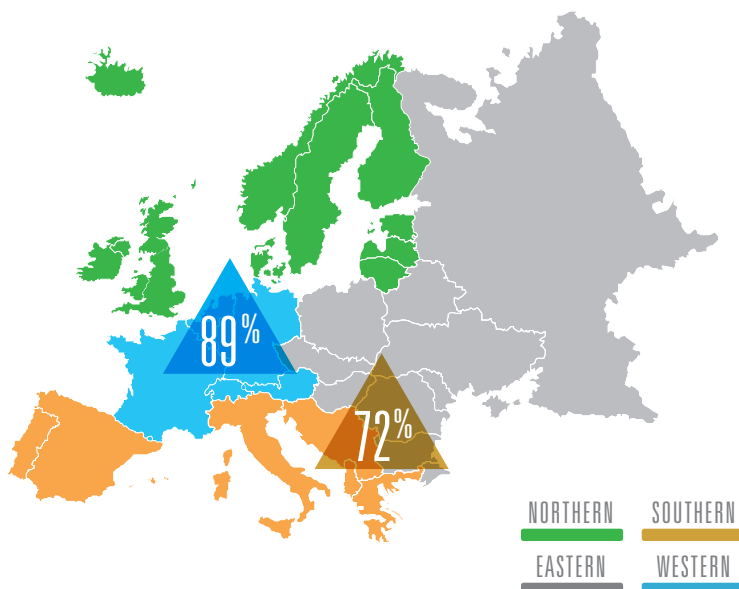
MORE THAN
1 YEAR
TO BE DIAGNOSED

AND IN SOME
CASES MORE THAN
5 YEARS

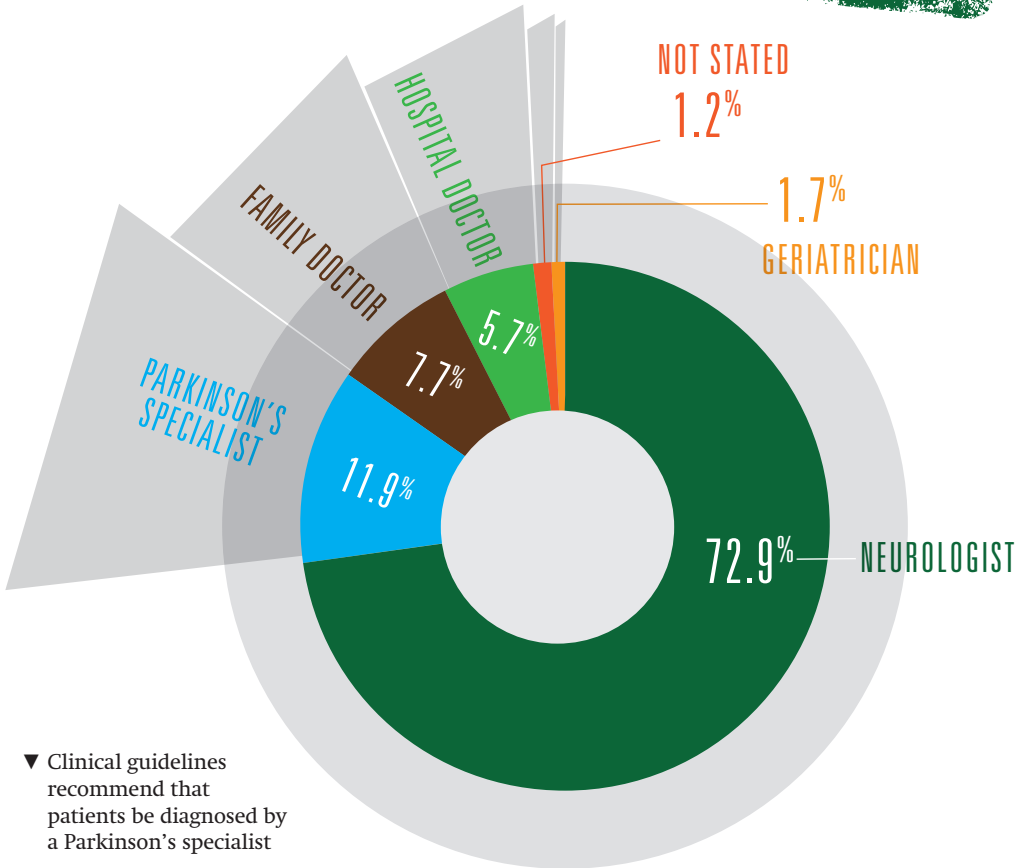
- ▼ At the time of diagnosis, most people with Parkinson's (71%) had seen either one or two doctors. A third doctor was involved in 14.5% of cases



- ▼ Western Europe has the highest proportion of people with Parkinson's diagnosed within 2 years, while Southern Europe has the lowest, suggesting a longer time to diagnosis



WHO GAVE THE DIAGNOSIS?



▼ Clinical guidelines recommend that patients be diagnosed by a Parkinson's specialist

KEY FINDINGS

PARKINSON'S SPECIALISTS DIAGNOSED **JUST 12%** OF THE SURVEY'S RESPONDENTS

- ▼ The large majority (79%) of people with Parkinson's are aware of a Parkinson's specialist in their country. However, many are not able to have regular visits to see them

20%

WERE NOT AWARE

79%

WERE AWARE OF A
PARKINSON'S SPECIALIST

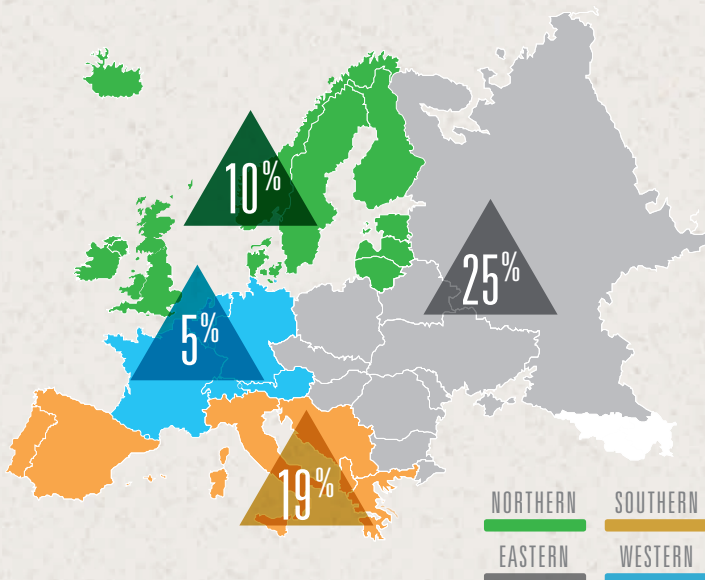
13%

DID NOT KNOW

7%

STATED NO

- ▼ The highest involvement of a Parkinson's specialist in diagnosis is seen in Eastern Europe (25%), with a similar involvement in Southern Europe (19%). Northern Europe sees 10% of diagnoses by a Parkinson's specialist; Western Europe sees 5%



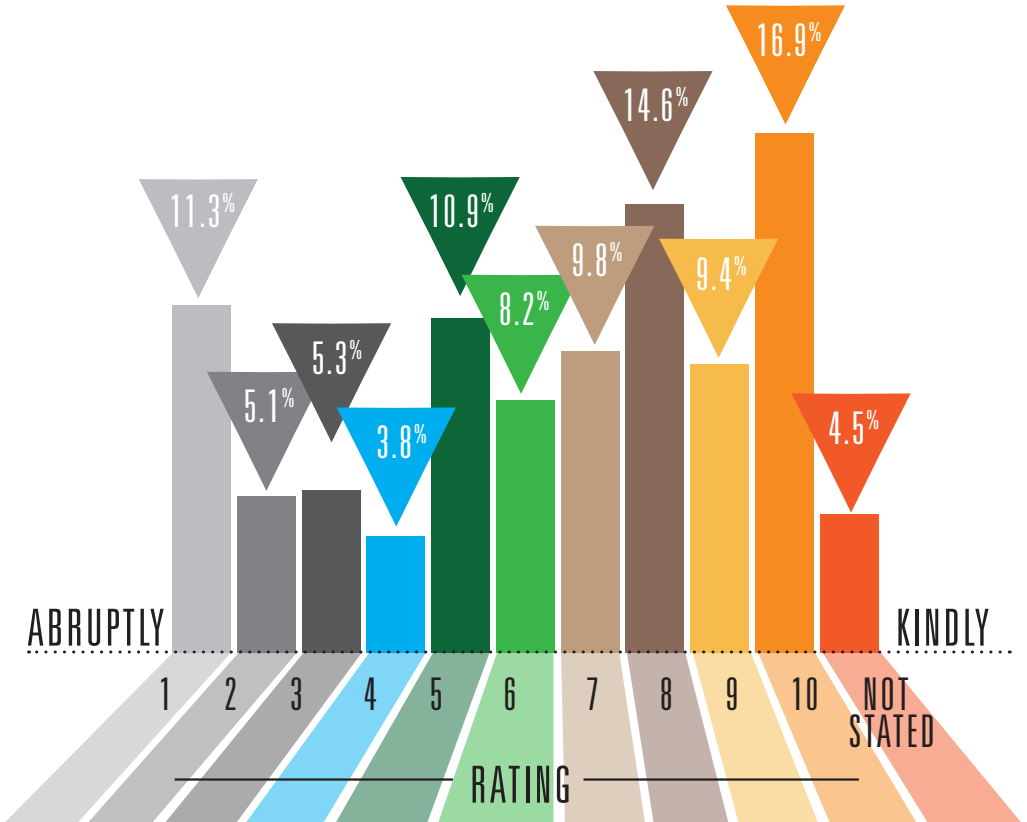
- ▼ The percentage of Parkinson's specialists giving a diagnosis has dropped through the 1990s

FROM
A HIGH
OF 62%
IN 1981-1985

TO 10%
IN 2006
-2010

Meanwhile, the percentage of people with Parkinson's receiving their diagnosis from a **general neurologist** has risen steadily from 53% before 1980 to a high of 77% from 2006 to 2010

HOW WAS THE DIAGNOSIS GIVEN? THE PATIENTS' PERCEPTION

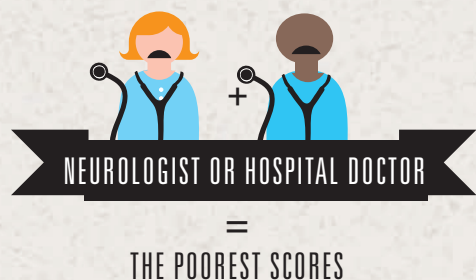


KEY FINDINGS

4 OUT OF **10**

PEOPLE FELT
THEY WERE
DEALT WITH IN A

“LESS THAN KINDLY”
MANNER BY
THEIR DOCTOR



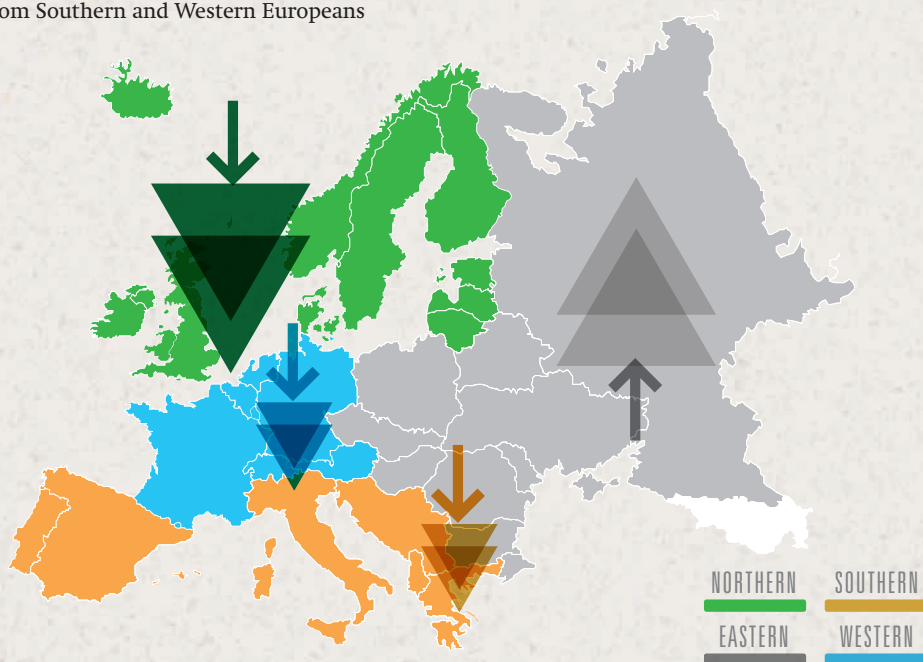
53%

FELT THE WAY THEY RECEIVED
THEIR DIAGNOSIS WAS
'GOOD' OR 'VERY GOOD'

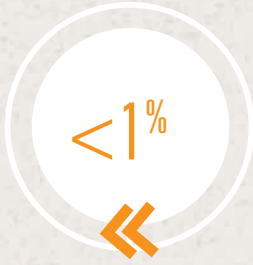
45%

SAID IT WAS
'POOR' OR 'VERY POOR'

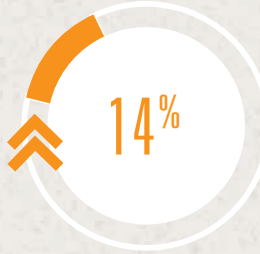
- ▼ Eastern Europeans showed the most satisfaction with how their diagnosis was handled. Northern Europeans were the least satisfied, but by only a small margin from Southern and Western Europeans



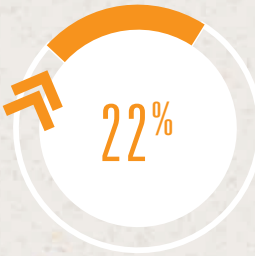
INFORMATION GIVEN AT THE TIME OF DIAGNOSIS



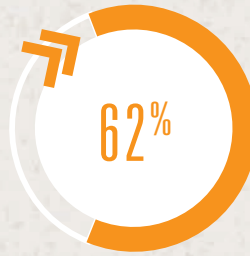
No information



Medication information



Detailed information



General information
(about Parkinson's only)

KEY FINDINGS

2 IN 3

RESPONDENTS
FOUND THE
INFORMATION
TO BE EITHER

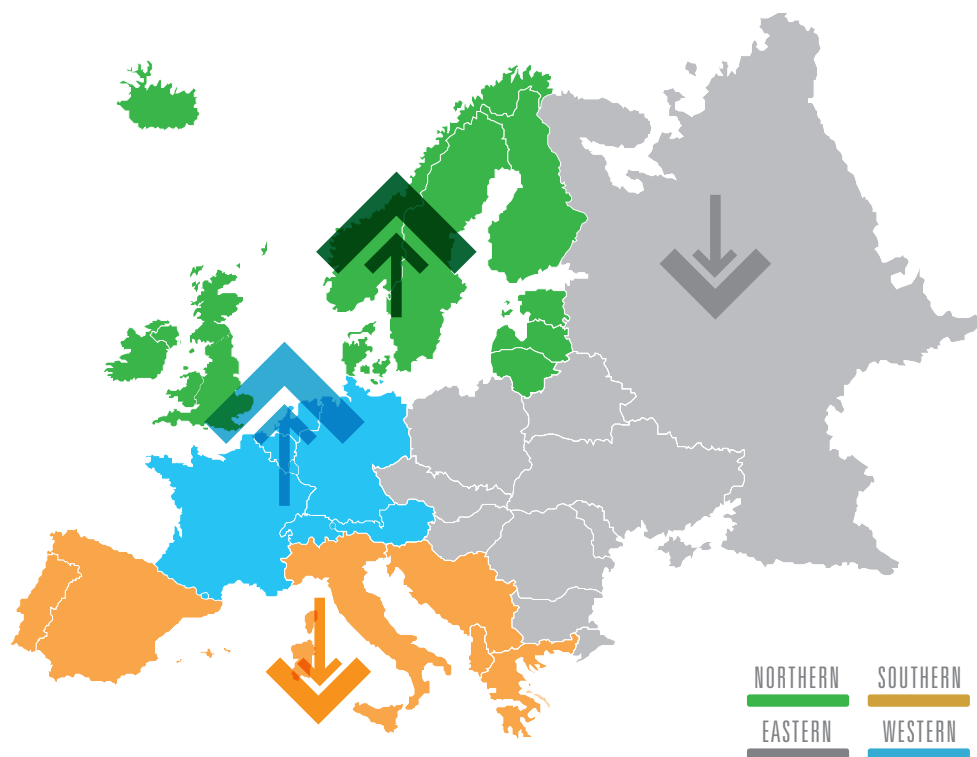
**"HELPFUL"
OR
"VERY HELPFUL"**

THE REMAINING

1 IN 3

FOUND THE
INFORMATION TO BE
"OF LITTLE HELP"

▼ Overall, the level of available information was reported to be better in Northern and Western Europe, and lower in Southern and Eastern Europe



Helpful or very helpful



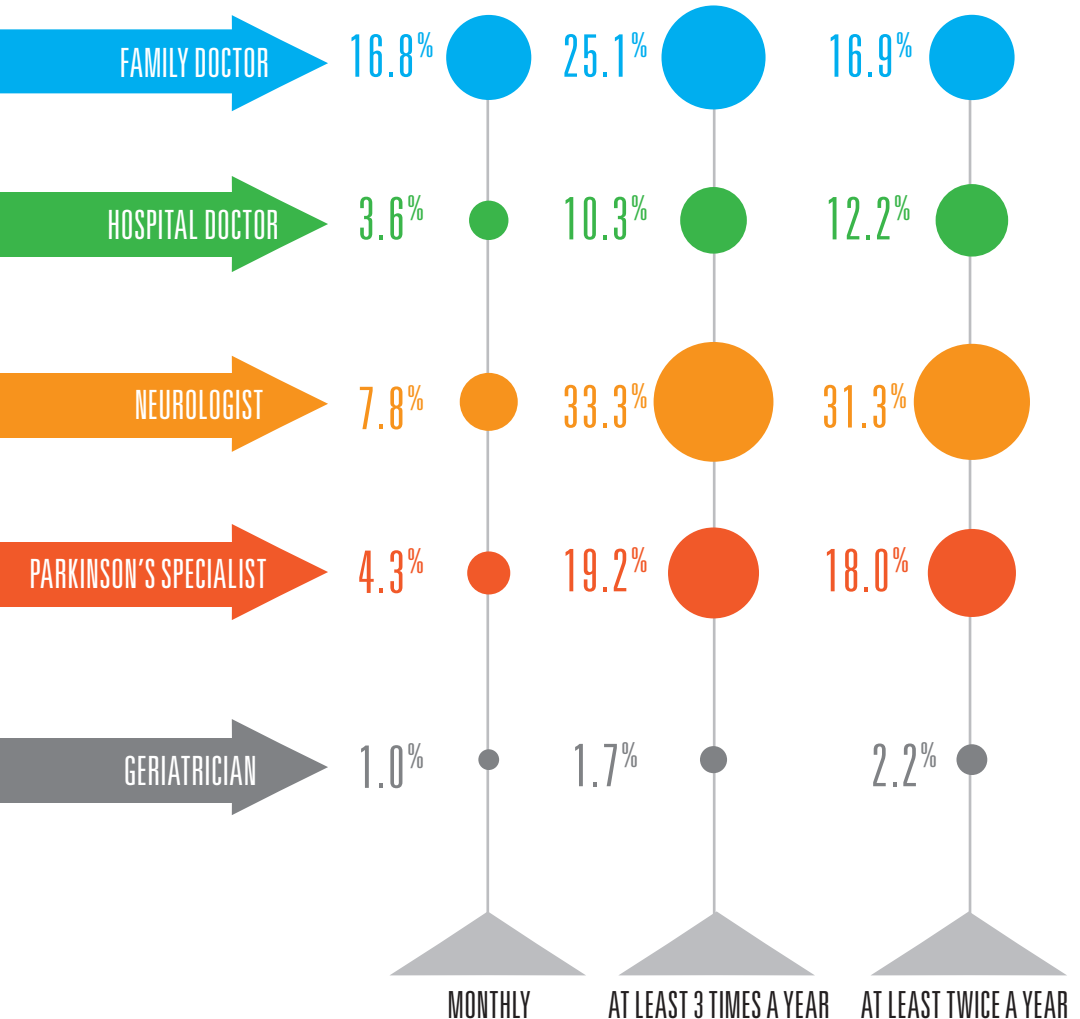
66%

Of little help



34%

FOLLOW-UP DOCTOR VISITS (WITHIN 2 YEARS OF DIAGNOSIS)



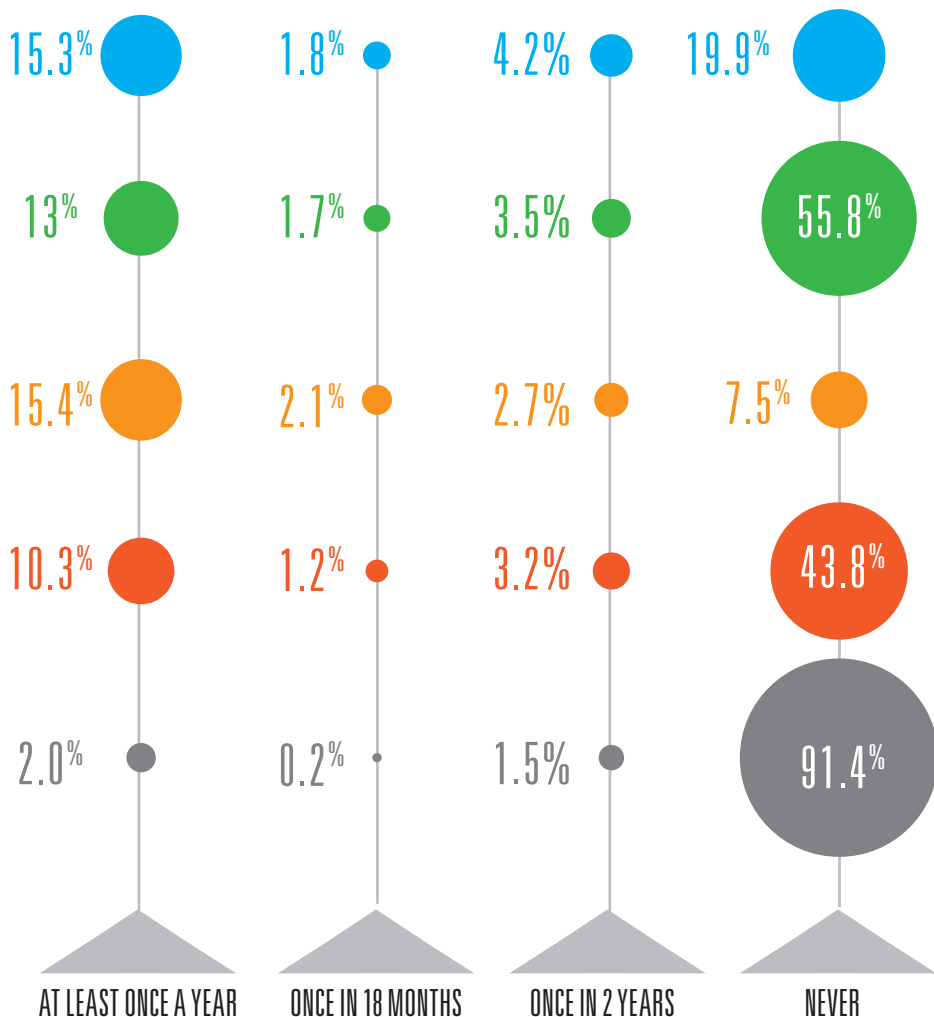
44%
NEVER SEE A
PARKINSON'S
SPECIALIST AND

91%
NEVER SEE
A GERIATRICIAN

KEY FINDINGS

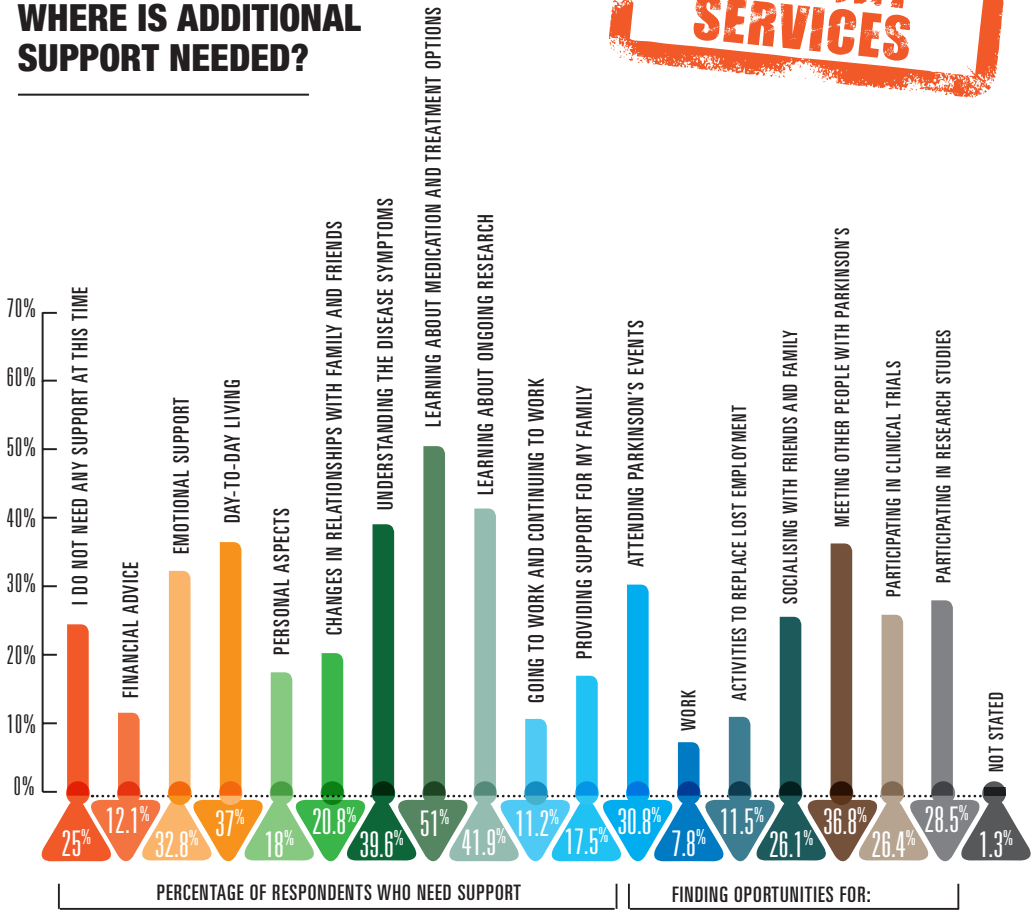
1/4 of respondents reported that they saw a family doctor at least three times a year

1/3 reported that they saw a neurologist at least three times a year



SUPPORT SERVICES

WHERE IS ADDITIONAL SUPPORT NEEDED?



KEY FINDINGS

75%

OF THE RESPONDENTS IN THE ENTIRE SURVEY INDICATED THAT THEY

NEEDED SUPPORT

ACROSS A VARIETY OF ASPECTS OF THEIR LIVES. OF THESE RESPONDENTS, MOST WERE INTERESTED IN

LEARNING MORE ABOUT PARKINSON'S **SYMPTOMS**, AND THE **TREATMENT OPTIONS** THAT ARE CURRENTLY AVAILABLE, OR **ONGOING RESEARCH**

INTEREST IN UNDERSTANDING THE DISEASE FURTHER WAS ALSO CONSIDERED IMPORTANT BY THE RESPONDENTS. MORE THAN A QUARTER (26%) SAID THEY WOULD BE INTERESTED IN 'PARTICIPATION IN CLINICAL TRIALS' AND 29% WANTED TO 'PARTICIPATE IN RESEARCH STUDIES'

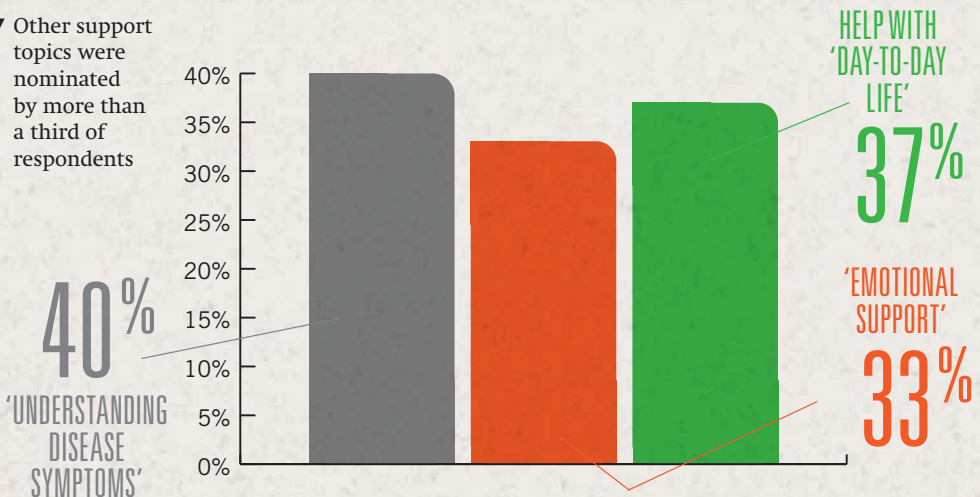
- ▼ The most common area where support was required was help in **learning about the medicines and treatment options available**



- ▼ Closely related to this was a request to be able to **better understand the ongoing research** that is being carried out in Parkinson's

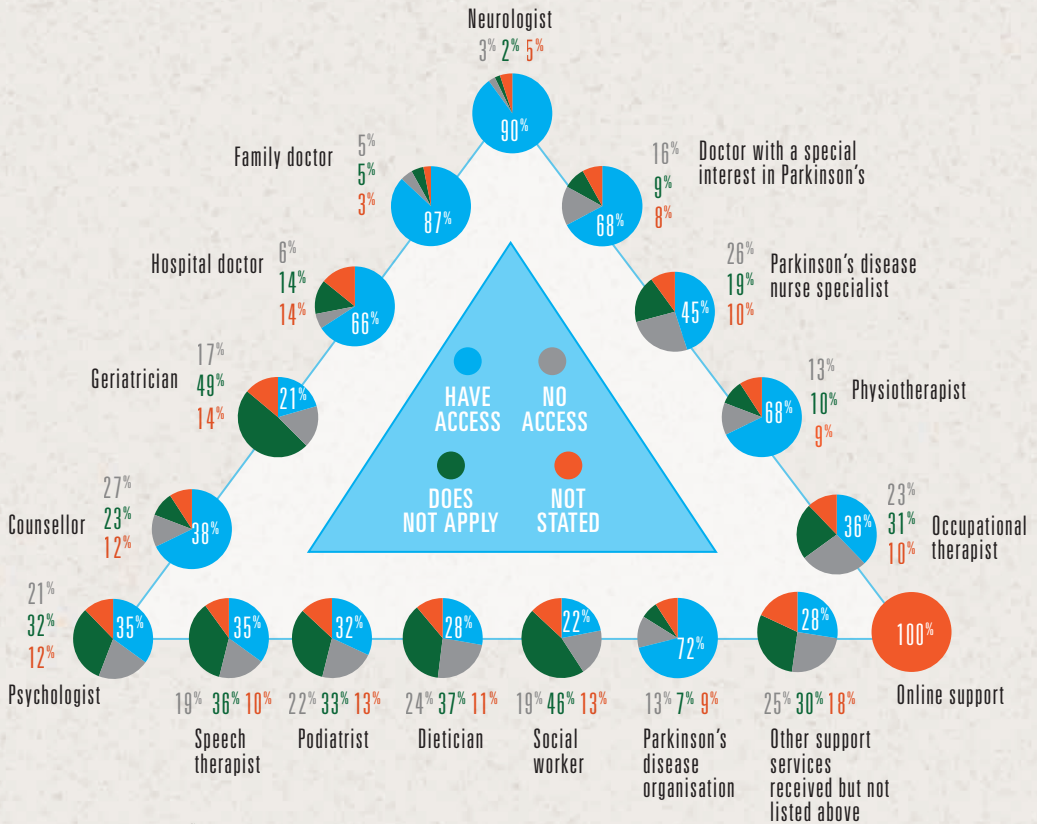


- ▼ Other support topics were nominated by more than a third of respondents



PATIENTS' ACCESS TO SUPPORT SERVICES

SUPPORT SERVICES



KEY FINDINGS

THE GREATEST LEVEL OF AVAILABILITY WAS REPORTED FOR NEUROLOGISTS AND FAMILY DOCTORS WITH

90%
AND
87%

OF THE RESPONDENTS INDICATING FULL ACCESS TO THESE SERVICES RESPECTIVELY. HOWEVER, NEARLY

1/3
OF THE SURVEY'S RESPONDENTS DO NOT HAVE ACCESS TO A PARKINSON'S SPECIALIST

▼ Across the survey access to support services was quite varied:

ACCESS TO DOCTORS WAS GENERALLY
CONSIDERED TO BE GOOD, AS WAS ACCESS
TO PHYSIOTHERAPISTS AND PARKINSON'S
ORGANISATIONS. BETWEEN
66% AND 90% OF RESPONDENTS REPORTED
THE AVAILABILITY OF THESE SERVICES

HOWEVER, AVAILABILITY
OF OTHER SERVICES
WAS CONSIDERED TO BE
SIGNIFICANTLY LOWER,
FALLING BELOW HALF
OF RESPONDENTS
IN ALL OF THESE CASES

▼ Our data highlights poor accessibility to **Parkinson's nurse specialists**:



45%

of patients
had access

26%

indicated
no access

19%

not stated
(suggesting no access)

▼ Particular services that were reported as having
limited or no availability were **counsellors, podiatrists**
and **psychologists**:



Services not
available

10%–20%

Unable to afford
these services



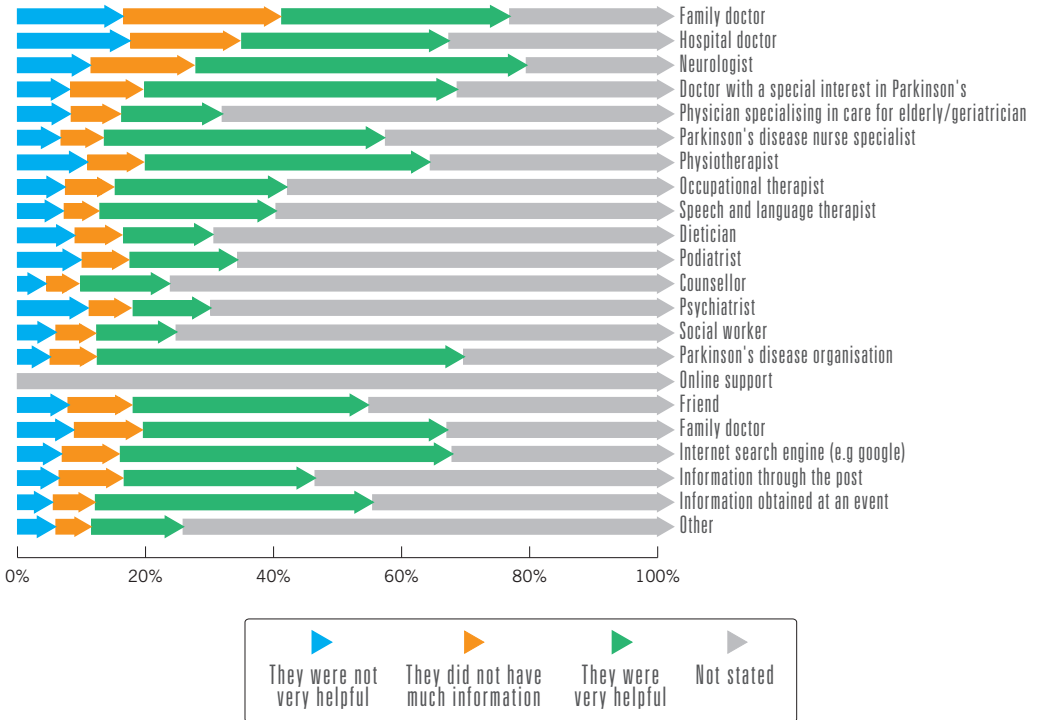
No access to
physiotherapists

ACCESS TO OTHER
PARAMEDICAL SERVICES
SUCH AS DIETICIANS,
SPEECH THERAPISTS
AND SOCIAL WORKERS
WERE REPORTED TO BE
LARGELY UNAVAILABLE

HELP WITH GAINING ACCESS TO RELEVANT SUPPORT SERVICES



▼ Who/what is the most helpful in assisting with gaining access to relevant support services?



KEY FINDINGS

FAMILY DOCTORS WERE RATED BY A HIGH PROPORTION OF RESPONDENTS, BUT USUALLY RECEIVED A MIXED RATING FROM EACH COUNTRY.

ACROSS THE SURVEY, THE PROFESSION WAS RATED AS:

'VERY HELPFUL'

36%

'DID NOT HAVE MUCH INFORMATION'

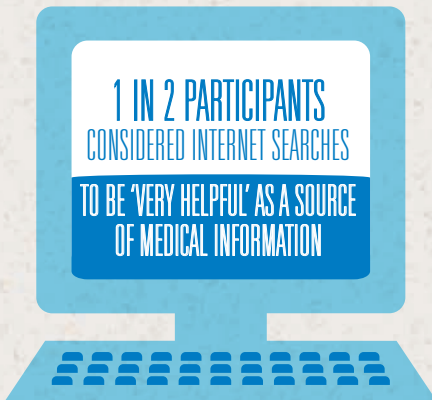
25%

'NOT VERY HELPFUL'

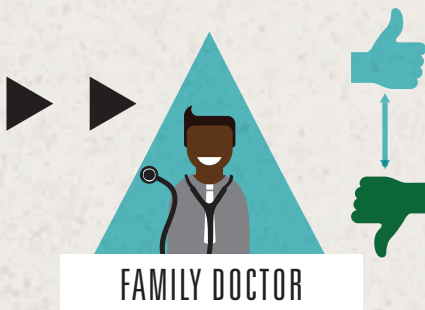
17%



- ▼ **Neurologists** were thought to be the most helpful of the doctor services in assisting with gaining access to other support services. Overall, they were rated as being 'very helpful' by more than half of the survey respondents



- ▼ This reflects the fact that **family doctors** are a very diverse group of practitioners, some of which can meet the needs of people with Parkinson's well, while others cannot



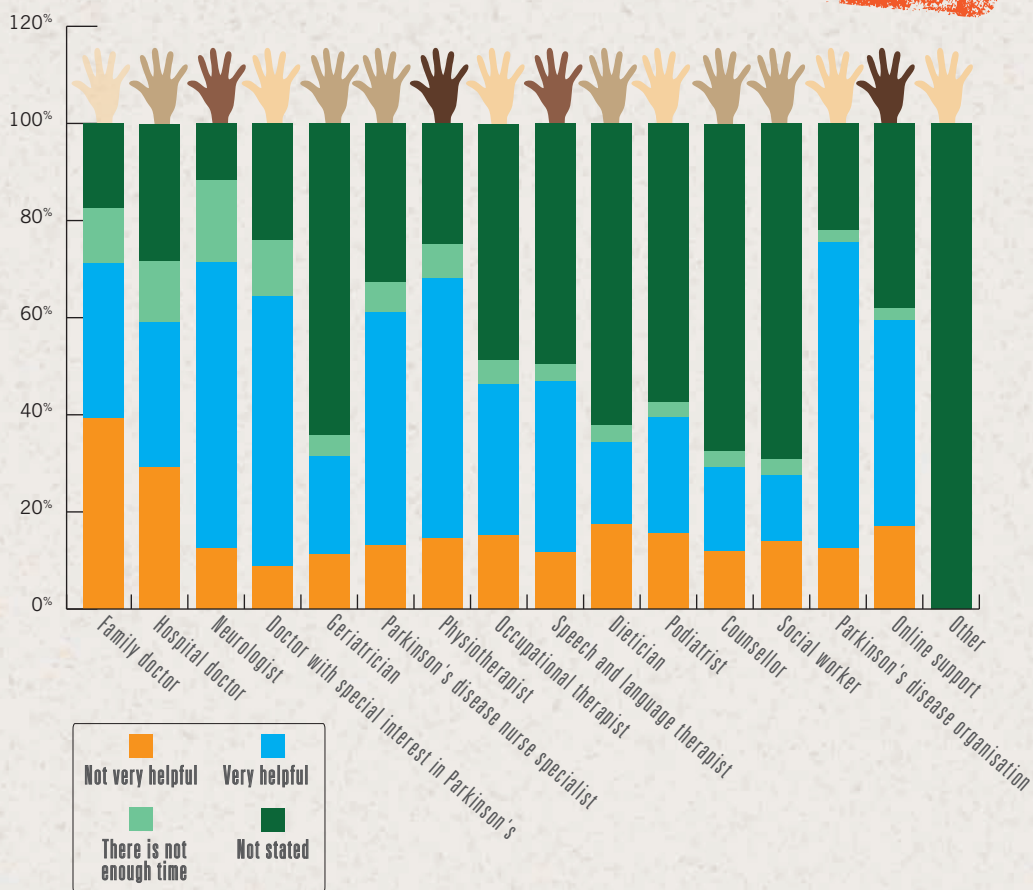
- ▼ **Parkinson's specialists** were rated highly and were viewed as 'very helpful' but received a lower accessibility rate than the neurologists



Of the paramedical disciplines,
physiotherapy
was the service used most
regularly, based on the number
of responses received. These
professionals were considered to
be a useful source of assistance,
and were rated as
'very helpful' by 45%
of respondents across Europe.
Other paramedical services were
used less frequently

HELPLESSNESS OF SUPPORT

SUPPORT SERVICES



KEY FINDINGS

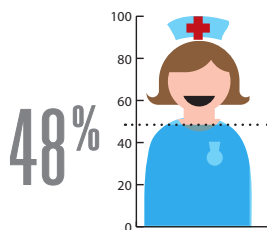
RESPONDENTS INDICATED THAT ALL OF THE DOCTOR CATEGORIES 'DID NOT HAVE ENOUGH TIME' FOR THEIR PATIENTS:

17%
FOR
NEUROLOGISTS

12%
FOR FAMILY DOCTORS,
HOSPITAL DOCTORS AND
PARKINSON'S SPECIALISTS.

IT IS IMPORTANT TO NOTE, HOWEVER, THAT THESE RATINGS VARIED GREATLY FROM COUNTRY TO COUNTRY

▼ **Nurses** were rated very highly in the countries where availability had been indicated: in the overall survey, almost half



of respondents rated specialist nurses as 'very helpful', although this varied greatly from country to country

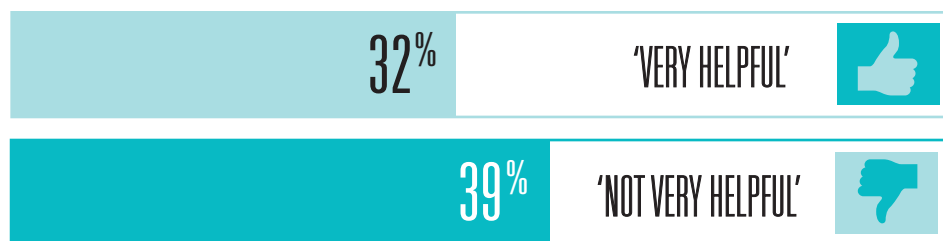
▼ **Neurologists** were generally considered to be the most helpful doctors in the care of people with Parkinson's



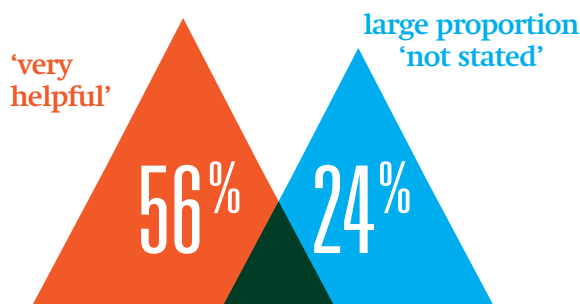
▼ This probably reflects the fact that they are consulted more frequently than the other specialties



▼ **Family doctors** again received very mixed ratings, which reflects the broad, mixed nature of this group of professionals



▼ **Parkinson's specialists** were also rated favourably, but by fewer respondents: they were rated as 'very helpful' by more than half of the overall survey, but a large proportion rated this service as 'not stated'. This suggests patients are not accessing disease specialists as often as they should

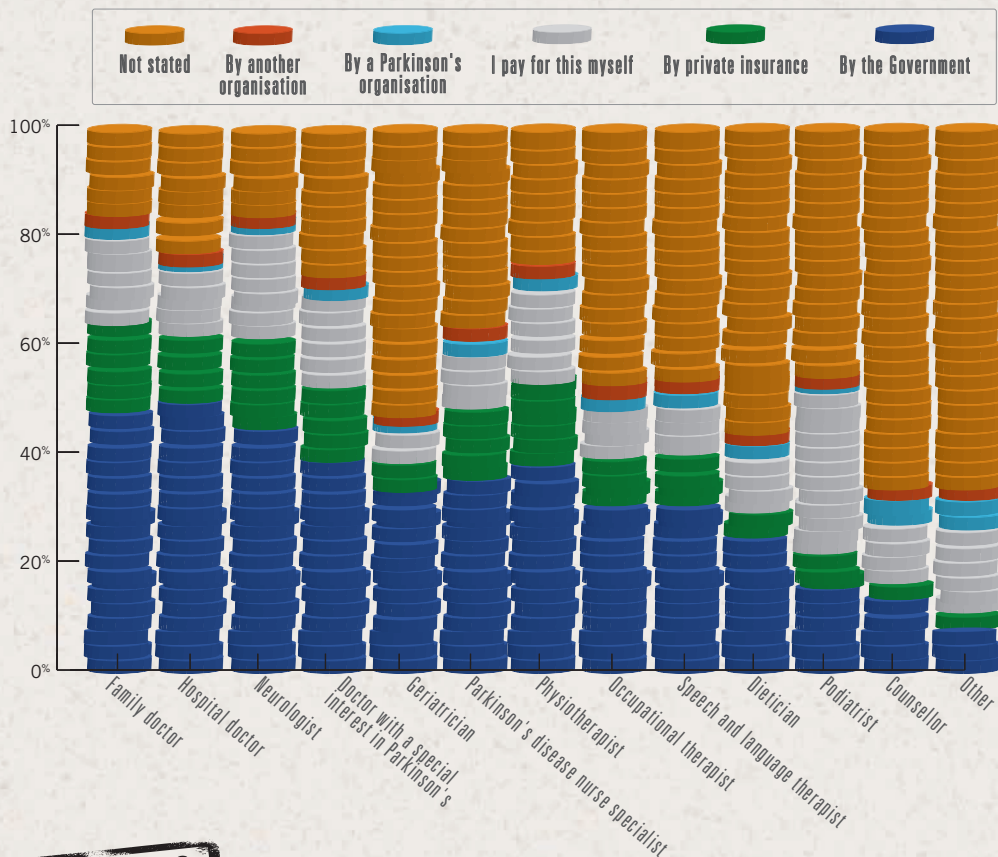


54%

More than half of the respondents rated physiotherapists as 'very helpful'. But it should be noted that, in many countries, this was the only paramedical service to receive any significant rating at all

FUNDING OF SUPPORT

SUPPORT SERVICES



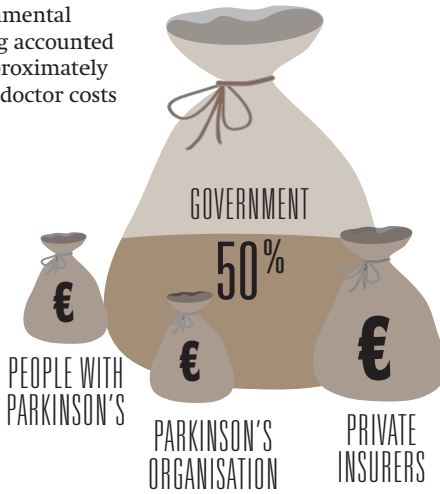
KEY FINDINGS

FUNDING WAS A HIGHLY VARIABLE TOPIC, WHICH DIFFERED DRAMATICALLY FROM COUNTRY TO COUNTRY.

ACCORDING TO THE RESPONDENTS, FOR EXAMPLE, THE UK WAS ALMOST ENTIRELY FUNDED BY A NATIONAL HEALTH SERVICE, SWITZERLAND WAS ALMOST ENTIRELY FUNDED BY PRIVATE INSURERS, WHILE

IN GREECE THE FUNDING OF TREATMENT BY VARIOUS DOCTORS INVOLVED A LARGE CONTRIBUTION FROM THE PEOPLE WITH PARKINSON'S THEMSELVES

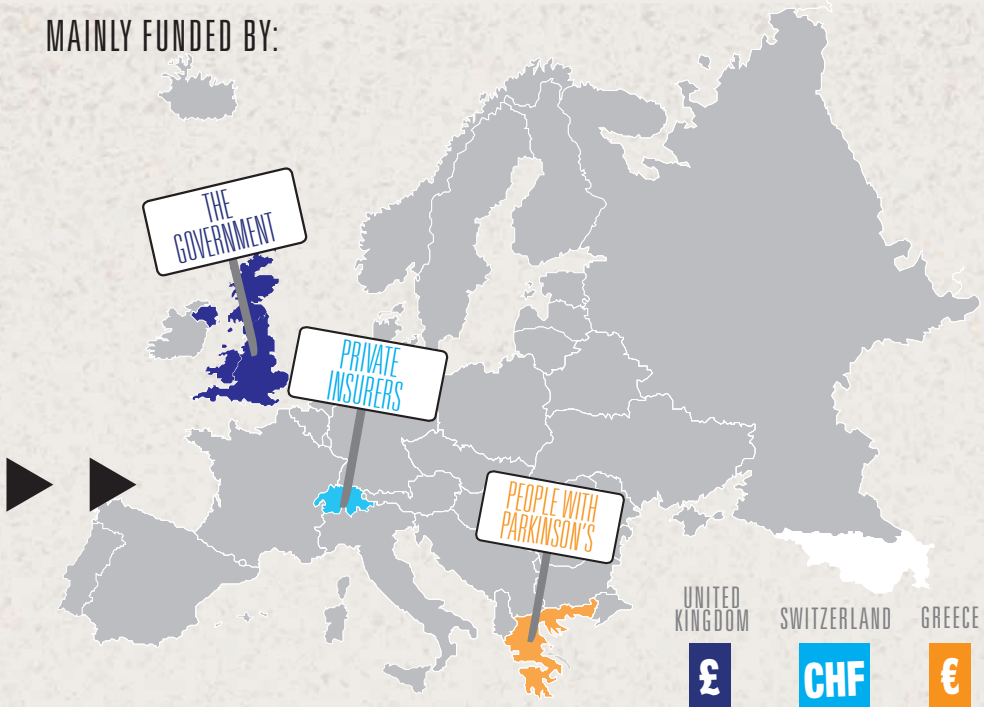
- ▼ Governmental funding accounted for approximately half of doctor costs



- ▼ The remaining costs were mainly covered by private insurance or were funded by people with Parkinson's. Small contributions were occasionally seen from Parkinson's and patient organisations

THE PROPORTION OF PAYMENTS MADE BY THE PEOPLE WITH PARKINSON'S THEMSELVES INCREASED FOR PARAMEDICAL SERVICES, WITH PODIATRY BEING THE MOST COMMONLY USED SERVICE THAT APPEARED TO BE LARGELY SELF-FUNDED

MAINLY FUNDED BY:



PARKINSON'S ORGANISATIONS AND SUPPORT GROUPS



- ▼ Most respondents are members of a national Parkinson's organisation



RESPONDER COMMENTS

287 reasons given

There were **287 reasons given** as to why people were not members of a national or local Parkinson's organisation

NON-MEMBERS

One third of these respondents said there was **no information about the organisations or that they did not know they existed**

1/3 had no information

1 in 6 said it was too soon to join

A further group considered that it was **too soon for them to join**, either because their diagnosis was recent, or because they felt no need for that type of support at present

Other reasons cited included the **lack of local facilities, travel difficulties, expense and time constraints** due to work etc

time/expense

▼ Of those that stated they were a member of a national Parkinson's organisation:

92% info good
or very goodThe vast majority thought that the information provided by their organisation was either **'good' or 'very good'**A further majority found the services of these organisations to be **'good' or 'very good'**73% services good
or very good72% less satisfied
with information**Southern Europe stands out as being distinctly less satisfied** with the level of information it provides, with lower ratings of 72% for information and 60% for services, **although these numbers are clearly still very positive**

MEMBERS

SUPPORT
GROUPS

64%

did not use
support group**Two thirds** of respondents reported that they did not use a support groupHowever, **1 in 4** did use a **local support group**

26% used group

9% used online
support groupA further 9% used an **online support group**A minority used **overseas support groups**1% used overseas
support group

split between Eastern and Northern compared to Southern and Western Europe

There is a **split between Eastern and Northern Europe**, which have a significantly higher proportion of people with Parkinson's who use support services. **This compares with Southern and Western Europe, where a majority do not use these services.** This split applies to all forms of support services

FREQUENCY AND EXPERIENCE OF HEALTHCARE APPOINTMENTS



34% OF PEOPLE SEE A DISEASE SPECIALIST ON A REGULAR BASIS



ONLY 18% OF PEOPLE SEE A SPECIALIST NURSE ON A REGULAR BASIS



PARKINSON'S SPECIALIST



PARKINSON'S DISEASE NURSE SPECIALIST

KEY FINDINGS

2 OUT OF 3
PEOPLE WITH PARKINSON'S
DO NOT SEE A DOCTOR
WITH A SPECIAL INTEREST
IN PARKINSON'S ON A
REGULAR BASIS.

PARKINSON'S
DISEASE NURSE
SPECIALISTS ARE
ALSO NOT SEEN ON A
REGULAR BASIS BY
MOST PEOPLE WITH
PARKINSON'S.

ACROSS THE SURVEY, ONLY
18%
OF RESPONDENTS SAW ONE
ON A REGULAR BASIS

REASONS FOR ARRANGING A HEALTHCARE APPOINTMENT

65% AS PART OF A FOLLOW-UP APPOINTMENT

12% ONLY WHEN MY SYMPTOMS HAVE CHANGED

13% ONLY WHEN I DO NOT FEEL MY MEDICATION IS WORKING CORRECTLY

7% OTHER

3% NOT STATED



KEY FINDINGS

A LARGE PROPORTION OF THE RESPONDENTS INDICATED THAT "IT IS NOT POSSIBLE" TO GET AN APPOINTMENT WITH SPECIALIST HEALTHCARE PROFESSIONALS SUCH AS:

occupational therapists – **51%**

41% – Parkinson's disease nurse specialists

dietitians – **53%**

THIS SUGGESTS THAT THESE SERVICES ARE EITHER NOT AVAILABLE TO THEM, OR PATIENTS ARE UNAWARE OF THEIR AVAILABILITY WITHIN THEIR OWN COUNTRY

HOW EASY IS IT TO GET AN APPOINTMENT?

▼ A significant percentage of respondents said "it is not possible" to get an appointment with a specialist healthcare professional such as:



51%

Occupational therapists



41%

Parkinson's disease nurse specialists



53%

Dietitians

PREPARING FOR AN APPOINTMENT

Approximately
1 in 4

people with Parkinson's in Europe do not make specific preparations for an appointment, preferring to wait for the healthcare professional to ask them questions

▼ Many people with Parkinson's are more proactive:

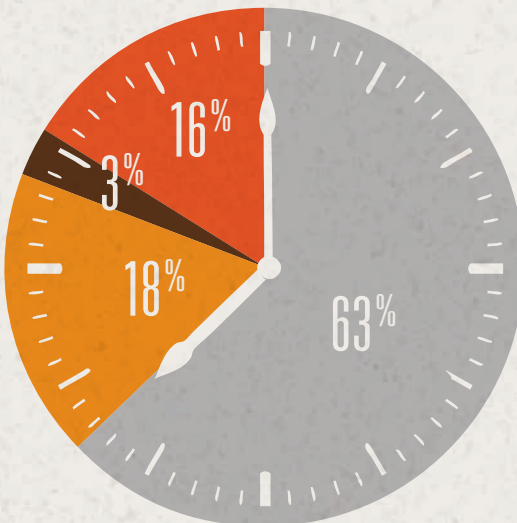
prepare specific questions for the healthcare professional in advance of the appointment

62%

39%

of respondents stated that they list symptoms, noting how they have changed since their previous appointment

APPOINTMENT DURATION



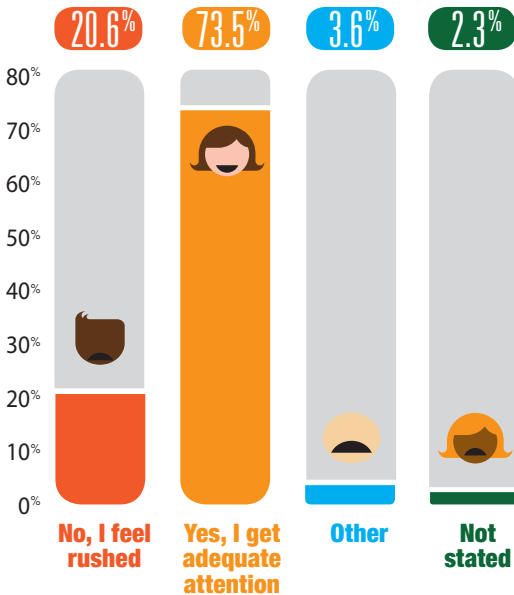
<10 MINUTES

15-30 MINUTES

>30 MINUTES

NOT STATED

APPOINTMENT SATISFACTION

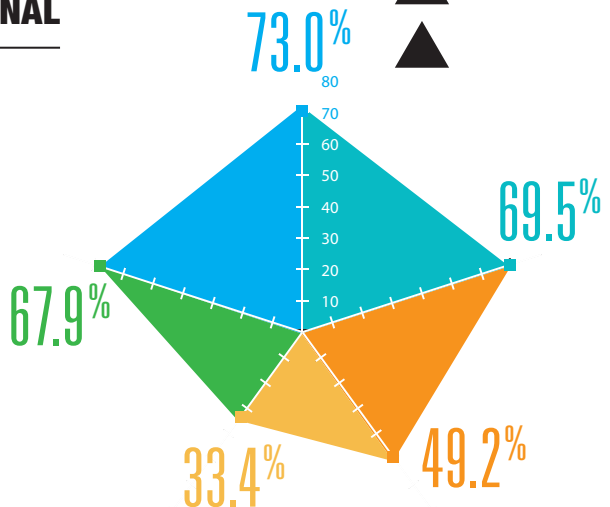


KEY FINDINGS

IT IS NOTICEABLE
THAT AT LEAST
1/2 OF PEOPLE WITH
PARKINSON'S
THOUGHT THAT
HEALTHCARE PROFESSIONALS
DO NOT SPEND MUCH TIME
DISCUSSING THE LIMITATIONS
OF PARKINSON'S AND
ITS DAILY IMPLICATIONS

PERFORMANCE LEVEL OF THE HEALTHCARE PROFESSIONAL

- ▶ Gives enough time to talk about patient concerns
- ▶ Is concerned about their responses as individuals
- ▶ Asks many questions about how the respondents are managing on a daily basis
- ▶ Asks respondents about the limitations of their Parkinson's
- ▶ Tries to help patients understand their symptoms



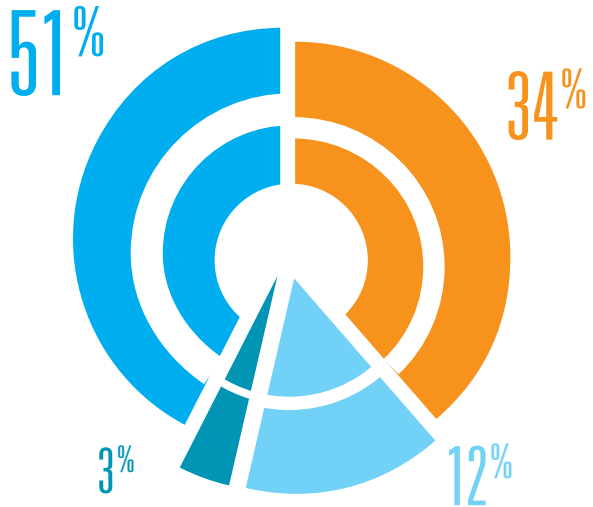
TREATMENT DECISIONS

■ THE DOCTOR AND I
DECIDED TOGETHER

■ THE DOCTOR
DECIDED FOR ME

■ I DECIDED AFTER
REVIEWING THE
OPTIONS AVAILABLE

■ NOT STATED



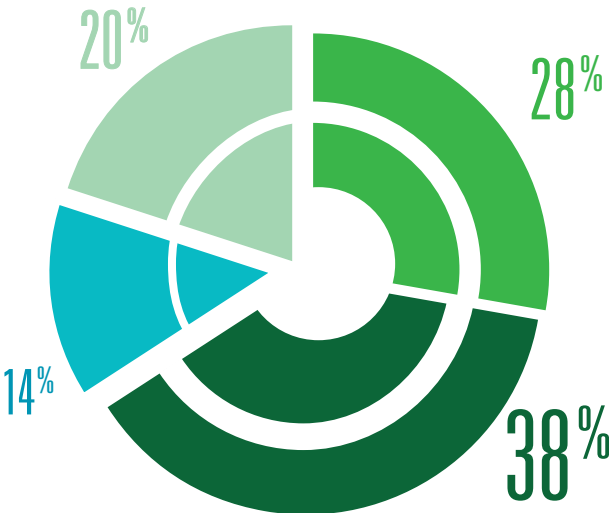
DISEASE MANAGEMENT DECISIONS

■ THE HEALTHCARE PROFESSIONAL
DECIDED FOR ME

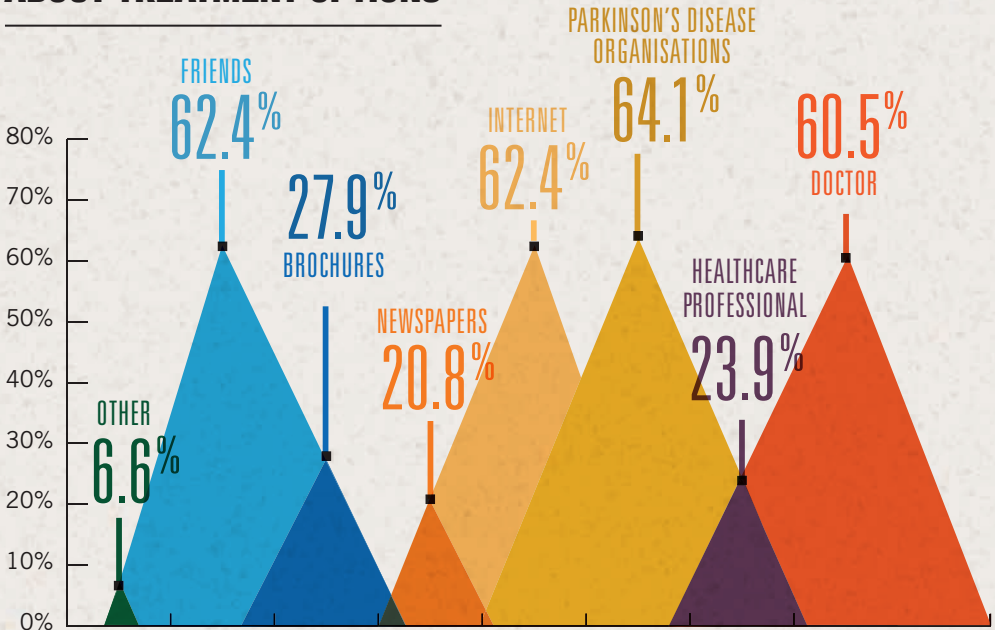
■ THE HEALTHCARE PROFESSIONAL
AND I DECIDED TOGETHER

■ I DECIDED AFTER REVIEWING
THE OPTIONS AVAILABLE

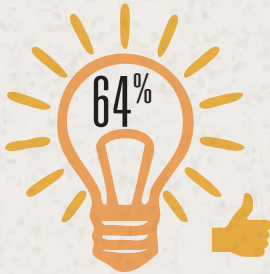
■ NOT STATED



SOURCES OF INFORMATION ABOUT TREATMENT OPTIONS



▼ The highest number of responses indicated **Parkinson's organisations** to be the key source of information



▼ The internet and friends also cited highly



KEY FINDINGS

ALTHOUGH MOST PATIENTS FELT THEY HAD BEEN INVOLVED

IN DECISIONS REGARDING THEIR DISEASE MANAGEMENT,

TRUE SHARED DECISION MAKING IS STILL RARE

CONTINUOUS CARE

INFORMATION AVAILABLE AT THE APPOINTMENT

▼ Information about more medical areas such as disease symptoms, medication and side effects was generally thought to be well explained and understood by a large proportion of people with Parkinson's in Europe. Information about other disease areas were not so good, however...



KEY FINDINGS

PEOPLE WITH PARKINSON'S ARE STILL STATING THAT THERE IS NOT A LOT OF INFORMATION AVAILABLE WITH REGARDS TO SEVERAL AREAS IMPACTED	BY THE DISEASE. ACROSS EUROPE, THE MOST COMMONLY HIGHLIGHTED OF THESE THROUGHOUT THE SURVEY WERE:	FINANCIAL HELP	49%
		FATIGUE	45%
		FOODS	45%
		SLEEPING	41%
		PAIN MANAGEMENT	40%

CARERS' PERSPECTIVE



▼ **Partners and carers are twice as likely to take notes during a consultation** than a person with Parkinson's. They are also more likely to ask questions than wait for the healthcare professional to ask

▼ The majority of carers:

sit in on appointments with people with Parkinson's

help people with Parkinson's to write lists of symptoms and changes prior to the appointment

help people with Parkinson's to prepare questions to ask the healthcare professional

91%

47%

59%

▼ More than half the partners/carers try to help people with Parkinson's understand disease symptoms and treatment

55%

KEY FINDINGS

THIS DATA
STRONGLY HIGHLIGHTS
HOW IMPORTANT
PARTNERS AND CARERS

ARE TO PEOPLE WITH
PARKINSON'S, AND
HOW INVOLVED
THEY ARE IN

THE PROCESS
OF INTERACTING
WITH THE PATIENT'S
HEALTHCARE TEAM

CONCLUSIONS AND RECOMMENDATIONS

By Professor Bastiaan Bloem and Professor Fabrizio Stocchi

DIAGNOSIS

Current clinical guidelines recommend that once Parkinson's symptoms are suspected by a family doctor, the patient should be referred to a movement disorder specialist for an accurate diagnosis within six weeks.^[1,2] Early referral to a specialist may reduce the period of uncertainty for patients awaiting a confirmed diagnosis, reduce the rate of misdiagnosis, and allow treatment to begin as early as possible.

In our survey, however, only 12% of patients received their diagnosis from a Parkinson's specialist. And one in three respondents took longer than one year to receive their diagnosis.

As multiple non-conclusive evaluations and delays in diagnosis can be a drain on healthcare resources,^[3,4] streamlining the referral process to a Parkinson's specialist and reorganising the secondary care

system^[5] provide a cost-effective means of improving care for people with Parkinson's.

The benefits of involving a specialist with expert understanding of Parkinson's may extend beyond the diagnostic

steps.^[6, 7] For example, the involvement of a movement disorder specialist results in greater adherence to key indicators of care quality in Parkinson's than when care is provided by a general neurologist.^[8] Furthermore, a US study reported that patients seeing a Parkinson's specialist were up to three times more satisfied with their care than those seeing a general neurologist, possibly due to enhanced quality of life.^[9]

Experiences in other neurological conditions also support the central role of specialists: stroke patients have better outcomes when treated on specialist stroke units rather than standard wards,^[10] while multiple sclerosis patients are more likely to be prescribed innovative therapies by specialists than by general neurologists.^[11]

Additionally, patients who are given the opportunity to take an active role in their own disease management – for example, by partaking in shared decision-making with their physician – have demonstrated better clinical outcomes, improved treatment adherence, greater quality of life, and lower healthcare costs.^[12-15] Future efforts should focus on further developing and implementing such patient-centered care for people with Parkinson's.

Our study did not examine the factors that currently limit access to Parkinson's specialists across Europe. However, barriers preventing access can include the need to travel to a specialist centre, a lack of funding, long waiting times, the need for a referral from a family doctor or a community neurologist, poor communication between



Professor Bastiaan Bloem

a family doctor and specialist, a lack of awareness among patients about the added value of a Parkinson's specialist, a low ratio of specialists to patients, lack of training of specialists and an inability to locate a Parkinson's specialist.^[16-18] Further analyses within national and local healthcare systems are needed to identify which factors are most applicable and allow action plans to be developed to address these.

The experience of receiving a diagnosis significantly impacts a patient's health-related quality of life.^[19] However, almost half (45%) of the survey respondents rated delivery of their diagnosis as 'poor' or 'very poor'. Lower scores were given when the diagnosis was handled by a neurologist or a Parkinson's specialist. In contrast, family doctors scored more highly, perhaps as they have more time or may know the patient on a more personal level.

Our data suggests that, although neurologists are superior in terms of specialist knowledge, they should improve their communication skills.

Communication skills training within the Continued Medical Education process could benefit general neurologists, Parkinson's specialists, and their patients.

Another concern identified was the value of information provided to patients at the time of diagnosis or shortly afterwards. Approximately 62% of the participants received general information following their diagnosis and, of those who responded, 34% felt the information was 'of little help'.

Additionally, less than 3% received any information on support organisations. As satisfaction with the explanation of the condition at diagnosis is directly related to quality of life,^[19] sufficient levels of appropriate information should be offered at this key point in patients' lives – for example, by developing more tailored information and materials that provide

essential information for patients but does not overwhelm individuals coming to terms with their diagnosis.

SUPPORT SERVICES

The combined motor and non-motor symptoms of Parkinson's require a multidisciplinary approach to ensure adequate treatment;^[20] and the EPDA Charter for People with Parkinson's Disease stipulates that access to additional support services should be available for all patients.

Although the level of evidence for different support services varies, it is important to

ensure that patients can access services with clinically proven benefits. The results from this survey have highlighted that access to allied health services is limited, particularly to occupational therapy, with only 36% of respondents indicating access to this service. However, only 11% indicated that they require further support with going to/continuing to work; it is possible, therefore, that the low

percentage of work-related responses could demonstrate a lack of understanding from the survey respondents.

This survey also investigated the availability of clinicians at varying levels of specialty. The results suggest that Parkinson's specialists remain less accessible than general neurologists and family doctors. Retrospective observational studies, however, suggest that clinical outcomes and survival rates in Parkinson's are improved with specialist care.

Family doctors were particularly accessible to Parkinson's patients; yet they also received the highest 'did not have a lot of information' rating.

“Future efforts should focus on developing and implementing better patient-centered care”

Professor Fabrizio Stocchi



Although perhaps understandable – family doctors by necessity cannot specialise in all conditions under their care^[21] – optimal management of Parkinson's symptoms requires detailed knowledge of the disease.

^[7] As a great many patients currently receive Parkinson's care from family doctors, these clinicians must either increase their understanding of the symptoms and appropriate care of Parkinson's patients, or refer their patients to a specialist who can ensure adequate treatment and support.

In terms of Parkinson's disease nurse specialists, many feel (based on everyday clinical experience) that they are a critical part of the multidisciplinary team approach to Parkinson's patients, but there is little evidence to support this impression.^[22,23] There is some recent data, however, that suggests patients cared for by a specialist nurse are more satisfied with their treatment and care than those consulting a general neurologist.^[24]

Specialist nurses can also improve the wellbeing of patients without impacting on healthcare costs through medication and symptom management support.^[24, 25] Moreover, clinical practice guidelines recommend regular consultations with a Parkinson's nurse specialist.^[26, 27]

Nevertheless, the Move for Change data highlights poor accessibility to these nurse specialists, reducing the realisation of their potential benefits. The costs and clinical effectiveness of a specialist multidisciplinary approach in Parkinson's are currently being investigated within the Specialist Parkinson's Integrated Rehabilitation Team Trial^[28] and a large trial in the Netherlands.^[29]

The survey participants also indicated that, although they may have access to one or all of the investigated services, each service ultimately 'does not have enough time' for them.

The internet has become an important source of medical information for people with Parkinson's,^[30-32] and these survey

results reflect this as internet searches were considered to be 'very helpful' by 52% of patients. It is feasible, therefore, to consider introducing online information to patients at an early stage of their treatment to supplement the care provided by their clinician. However, as with all disease management support, evidence will be required to support clinical – and cost-effectiveness of such initiatives.

CONTINUOUS CARE

According to the Move for Change survey, a large majority of consultations across

Europe are arranged as part of a routine follow-up process, suggesting that treatment is driven by the healthcare professional and not by patient needs. Most patients feel they receive adequate attention from the healthcare professional during their consultations, which commonly last between 15 and 30 minutes. Satisfaction levels increased with longer consultations. (It is important to note that this data may

not be an accurate representation of clinical consultation satisfaction – dissatisfied patients are likely to be those with a poor relationship with their clinician or Parkinson's support networks, and may not have been aware of the Move for Change survey in order to respond.)

The healthcare professionals that were consulted most frequently – and had the shortest access time – were family doctors and neurologists. Yet, only half of the patients had regular scheduled appointments with their neurologist (53%), suggesting there could be under-treatment in the remaining patients.

We feel that the complex and progressive nature of Parkinson's justifies periodic consultations with an expert in Parkinson's, interweaved with consultations with generically active professionals.

“These survey results have highlighted that access to allied health services is limited”

It is crucial that collaboration between patients and healthcare professionals takes place to ensure that consultations are arranged at an appropriate time in order to achieve the best possible clinical outcomes. We recommend that patients or their carers should be leading the timing of the consultations, so they are held at a stage when the patient has poignant points to discuss.

Previous studies have shown that adherence to medication is improved if there is better collaboration between patients and clinicians,^[33] and compliance to medication in Parkinson's has been shown to reduce healthcare costs.^[34] Involving patients in medical decisions, therefore – using shared decision approaches, for example – can also help to reduce costs.^[35, 36] Additionally, better care, professionalised networks and an active role for patients can be implemented without changing the reimbursement system.^[37]

Most patients felt that the level of information in several Parkinson's-related areas was limited, particularly in areas of fatigue, pain management and advanced disease care. This could lead to a lower number of patients being able to make an informed decision regarding their disease management. Healthcare professionals should, therefore, provide patients with certified sources of information to avoid any bias and potential dangers of uncertified information.

Most patients in the survey did appear to make collaborative decisions regarding disease and treatment with their family doctor, which would suggest that they are content with the outcomes. However, it can rightly be questioned whether these decisions were truly made as part of a shared decision process – where patients have full access to all medical information and can weigh the importance of each element of the

decision process.^[38, 39] Furthermore, the low percentage of consultations arranged due to dissatisfaction with medication (13%) could be correlated with the percentage of those who are not involved in treatment (34%) and disease management (28%) decisions. This data suggests it is clinician-driven treatment rather than patient-driven care, and indicates that consultations are not being held when they should be in order to optimally treat the patient.

It has been demonstrated that 'participatory medicine' – where patients act as partners in their care with their healthcare professionals – results in improved care and can also contain costs.^[40] Therefore,

it is important that the dialogue between patients and healthcare professionals is improved so that patients become empowered enough to discuss changes in their condition and understand their treatment regimen, while the healthcare professionals maintain the power to ensure the treatment plan is appropriate for the patient. ■

“Better patient care can be implemented without changing the reimbursement system”

Professor Bastiaan Bloem is a consultant neurologist at Radboud University Nijmegen Medical Centre, the Netherlands.

Professor Fabrizio Stocchi is a professor of neurology, and director of the Parkinson's Disease and Movement Disorders Research Centre at the Institute for Research and Medical Care, IRCCS San Raffaele, Italy.

These conclusions and recommendations have been taken directly from three in-depth Move for Change articles, authored by Professor Bloem and Professor Stocchi, that appeared in the *European Journal of Neurology* between 2011 and 2014. To download these articles in full, visit www.epda.eu.com/move-for-change.

SURVEY LIMITATIONS

It is important for readers to note the possibility of response bias due to the methods by which the Move for Change surveys were promoted and completed. By Professor Bastiaan Bloem and Professor Fabrizio Stocchi

1. As the survey was only available online, participation was limited to those with internet access who are likely to be well informed about their disease, may consult with their clinician more frequently, have higher expectations from physicians, and have a more favourable view on the quality of their consultations than patients who are less well informed. As such, the responses in this survey may be negatively biased in relation to the level of information received from the doctor. However, patients with internet access are also most likely to seek access to the best care^[41] so, if anything, our inability to include patients without such access underscores the unmet needs in Parkinson's care in Europe.
2. The absence of a universal definition for what constitutes a 'doctor with a specialist interest in Parkinson's' or 'Parkinson's specialist' may have resulted in ambiguity for some respondents. For example, a patient seeking good medical care may not always be aware whether their doctor has undergone specialist training or has considerable clinical experience in Parkinson's management.
3. Some questionnaires could have been completed by individuals without connection to Parkinson's.
4. Due to the websites through which the survey was made available, those completing the survey may have had a higher awareness of the EPDA or a national Parkinson's Disease association. As a result, respondents who are members of such organisations may be over-represented. This could have an upward effect on the approval ratings for information and support from these associations. These patients are also more likely to be actively involved in managing their disease, and be more aware of the options available to them. Again, this could lead to underestimation of the unmet needs identified by this survey.
5. The potential over- or under-representation of countries should be considered as the distribution of respondents from each country within the European sample does not necessarily correlate with the national population. Any interpretations about international differences in care delivery should therefore be made cautiously.
6. There is potential variability in the need for particular services due to the individual nature of Parkinson's. A patient with the disease who does not have significant speech or swallowing problems would not require a speech therapist and could therefore be unaware of having access to this service.

Nonetheless, an online survey format provides several advantages: it can be completed at home at any convenient time, there is no need to arrange for transport to/from a clinical practice, and there is no burden for the healthcare professionals other than to direct their patients to the survey. In addition, online questionnaires achieve slightly higher completion rates than mailed questionnaires.^[42]

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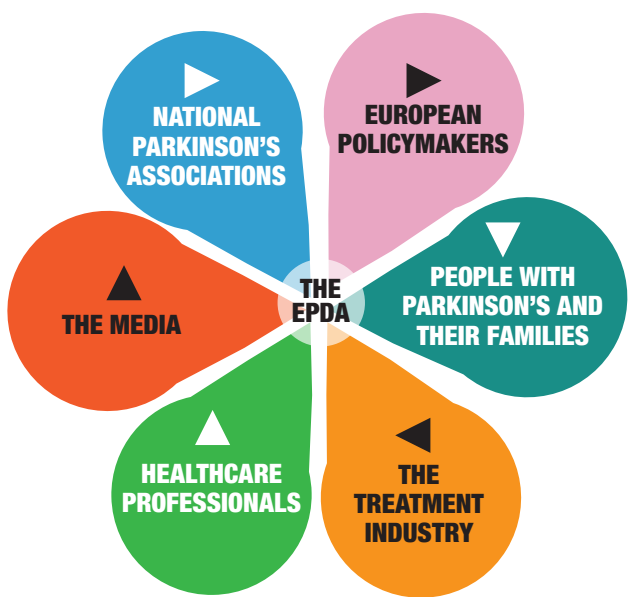
ABOUT THE EPDA

The EPDA is the only European Parkinson's disease umbrella organisation. We represent national Parkinson's organisations in 36 countries across Europe and advocate for the rights and needs of more than 1.2 million people with Parkinson's and their families.



THE EPDA MISSION

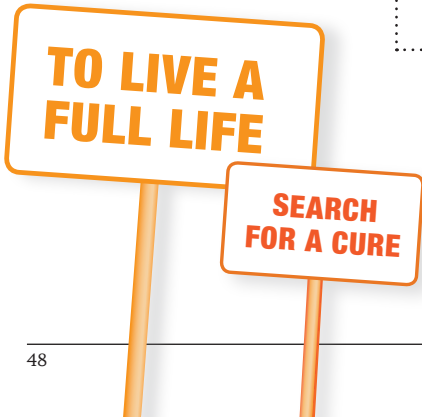
We aim to become the leading voice for Parkinson's in Europe by providing innovative leadership, information and resources to:



By doing this, we hope to raise the profile of Parkinson's and enable people living with the disease to be treated effectively and equally throughout Europe.

THE EPDA VISION

To enable all people with Parkinson's in Europe to live a full life while supporting the search for a cure.



WHAT DOES THE EPDA DO?

By working with our members – who represent the needs of individual people with Parkinson's and their families at a national level – the EPDA aims to:

1

**POSITIVELY INFLUENCE PARKINSON'S
STAKEHOLDERS TO CHALLENGE
EXISTING MINDSETS, SHIFT ATTITUDES
AND REMOVE THE HURDLES THAT
PREVENT PEOPLE WITH PARKINSON'S
FROM RECEIVING EARLY AND
APPROPRIATE TREATMENT AS WELL
AS INDIVIDUALISED CARE**

2

**INCREASE PUBLIC
AWARENESS OF
PARKINSON'S AS A
PRIORITY HEALTH
CHALLENGE**

3

**SUPPORT THE
DEVELOPMENT OF
NATIONAL PARKINSON'S
ORGANISATIONS
THROUGHOUT EUROPE**

4

**HELP REDUCE
STIGMA AND REMOVE
DISCRIMINATION
AGAINST PEOPLE WITH
PARKINSON'S**

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This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There is no handwriting or other markings on the paper.



ACCESS TO A
NUMBER OF
ALLIED HEALTH
SERVICES –
ESPECIALLY
PARKINSON'S
DISEASE NURSE
SPECIALISTS
– IS LIMITED
ACROSS EUROPE

*Patient satisfaction
levels increased with
longer consultation
meetings*

**DOCTOR
CONSULTATIONS
ARE NOT BASED
ON A PATIENT'S
NEEDS**

**TRUE SHARED
DECISION MAKING
IS STILL RARE
WITH REGARDS
TO PEOPLE WITH
PARKINSON'S
TREATMENT AND
MANAGEMENT**