

# PARKINSON'S CARERS SURVEY REPORT

New data collection with the goal to better understand the challenges carers of people with Parkinson's face in their daily lives



*The voice for Parkinson's in Europe*

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## INTRODUCTION

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Carers of people with Parkinson's face physical, medical, financial, and emotional challenges that may have a substantial impact on their own health, wellbeing, and quality of life. At the European Parkinson's Disease Association (EPDA), we work hard to raise the profile of carers with European and national decision makers and other stakeholders, and seek to improve their quality of life as best as we can.

In January 2019, the EPDA began a new data collection project with the goal of better understanding the challenges carers of people with Parkinson's face in their daily lives. The findings of this survey provide evidence demonstrating the individual and societal cost consequences that caring has on individuals – consequences that are too often ignored by governments and decision makers across Europe.

We hope that the results of this survey can lead to the development of tangible tools and solutions for carers, people with Parkinson's and the wider Parkinson's community.

*"Carers are such an important part of the Parkinson's community; they are the foundation who support their loved ones who are physically living with the condition.*

*Unfortunately, carers' needs and quality of life are all too often overlooked; this can lead to devastating and lasting effects on the individual and society at large."*



**Russell Patten**, Director General of the EPDA

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## PARTNERSHIP

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This data collection project was made possible with the support by our partner Air Liquide Healthcare. Air Liquide provided funding and organised the workshop held in Paris in April 2019, as well as the submission of a poster and an abstract that were presented at the MDS Virtual Congress 2020.

The survey results and individual data are the property of the EPDA.



*The voice for Parkinson's in Europe*

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# METHODOLOGY

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## This project was structured into five phases:

### Literature review

In January-February 2019, we reviewed existing research literature and similar surveys to highlight key themes and issues that are common to carers of people living with Parkinson's (PwPs) and other neurodegenerative conditions.

### Interviews

In March and April 2019, the EPDA conducted around 20 interviews with carers of people with Parkinson's in eight European countries. These interviews allowed us to obtain authentic and meaningful information about the physical, emotional, and financial challenges carers face, and about the impact these challenges have on their quality of life. They also revealed the use and availability of support services and tools in different European countries.

### Interactive workshop meeting

The data gathered during the interviews with carers was analysed during a workshop meeting that was held in Paris in April 2019. People with Parkinson's, carers and EPDA member organisation representatives joined in a collaborative one-day session. The feedback and input from this session was used in conjunction with the interview results to help draft the final survey.

### Online survey

The survey questionnaire was co-built with representatives of EPDA national member organizations to address carers' emotional, physical/medical, or financial challenges.

The online survey consisted of 44 questions with multiple choice answers, and was available in 14



languages (Czech, Danish, Dutch, English, Finnish, French, German, Italian, Maltese, Polish, Portuguese, Slovenian, Spanish and Swedish). The survey was open between 10 June and 6 September 2019 and promoted by the EPDA's member organisations and network of healthcare professionals and stakeholders.

‘The EPDA conducted around 20 interviews with carers of people with Parkinson’s in eight European countries’

### Data analysis and report

Data was analysed in the final quarter of 2019. The results from the survey in various languages were combined and screened for duplicate results (each result was compared using the IP address and duplicate answers were removed). 1,790 individuals, from 30

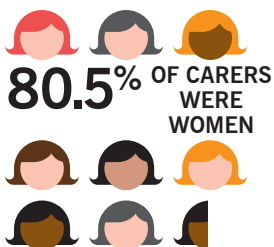
European countries, answered the questionnaire. Due to the high number of respondents, the confidence interval (margin of error) in reported results is 5% and the confidence level is 95%.

A poster displaying key findings of the survey was presented at the MDS Virtual Congress 2020.

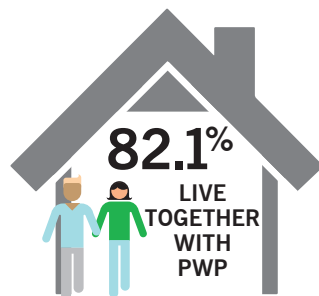
An abstract entitled Carers of People Living with Parkinson's Disease, the 2019 European Realities (authored by Dr Hélène Rossinot, Prof Pablo Martinez-Martin, Prof Per Odin, Prof K Ray Chaudhuri, Dr Catherine Billoët and former EPDA Vice-President Susanna Lindvall) was presented at the MDS Virtual Congress 2020.

# RESULTS

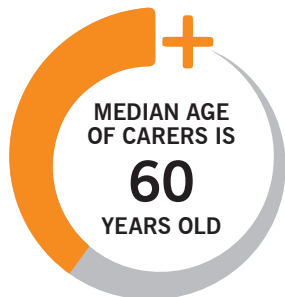
## About the carers



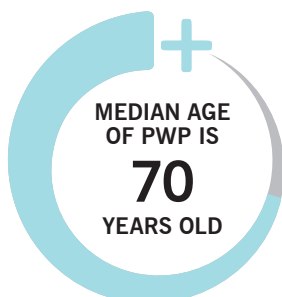
In this study, **68.3%** of carers were caring for a man.



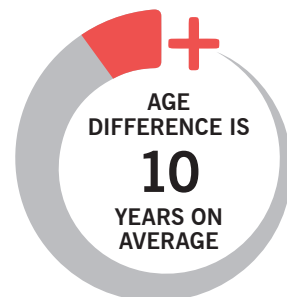
A large majority of the carers, **69.2%**, are a **spouse or partner** of the person with Parkinson's.



With the **youngest** being **19** years old and the **oldest** **96**.

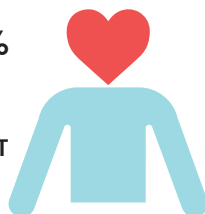


With the **youngest** being **32** years old and the **oldest** **98**.



**41.9%** of respondents are **employed** (either full-, part-time, or self-employed).

**58.1%** OF CARERS ARE NOT IN EMPLOYMENT



**43.1%** OF CARERS ARE RETIRED

<sup>1</sup> A majority of the respondents (45%) came from either the UK or Italy.

# RESULTS

## ► About the carers



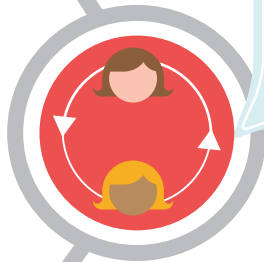
ONLY A THIRD  
**33.2%**  
OF CARERS  
SHARE THEIR  
DUTIES WITH  
SOMEONE ELSE

In **France** and in **South-Western Europe**, carers are more likely to share the care of the patient (43% and 49% respectively). In other countries, the percentages of carers not sharing their duties are extremely high (76% in **Benelux**, 79% in **UK & Ireland** and 80% in the **Nordics**.)

**43%**  
OF THE INDIVIDUALS  
CARING FOR A PERSON  
WITH PARKINSON'S  
DIAGNOSED MORE THAN  
10 YEARS AGO DECLARE  
THEY SHARE THE CARE

Only **18.2%** of the carers of a person with Parkinson's diagnosed less than **4 years ago** declare they share the care.

THE SHARING OF CARING  
DUTIES WITH SOMEONE ELSE  
BECOMES MORE COMMON  
THE LONGER SOMEONE  
HAS BEEN DIAGNOSED  
WITH PARKINSON'S



On average, respondents spend **7.6 hours a day** on caring tasks.

**10.6%** of them even described their role as **24 hours of caring a day**. The average time spent on caring also increases as the duration since the diagnosis increases.



CARERS SPEND  
AN AVERAGE OF  
**9 HRS**  
PER DAY ON  
CARING TASKS

Carers of people with Parkinson's diagnosed more than 10 years ago declare spending an average of **9 hours per day on caring tasks**, compared to 6 hours for a diagnosis that was less than 4 years ago.

# RESULTS — WHAT ARE THE CHALLENGES FACING CARERS?

## ► Emotional challenges

The challenges facing carers of people with Parkinson's can be grouped into three distinct categories:

### 1. EMOTIONAL



### 3. FINANCIAL



STRESS IMPACTS **53.9%**



**48.8%**



ANXIETY IMPACTS **48.8%**



Emotional and psychological challenges are the most common category of challenges facing carers; they affect nearly all – 95.9% – of them.

Of these, stress is the most common challenge, experienced by more than half of carers, followed by fear of not being able to care in the future and anxiety.

**42.9%**  
FEELING  
LETHARGY  
AT HOME



Feeling lethargic at home was reported as the most common physical effect of caring.

**40.8%**  
FEELING  
OVERWHELMED

But almost as many carers reported feeling overwhelmed.

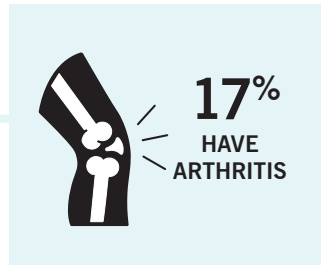
# RESULTS

## ► Physical challenges

Carers also face a lot of physical and medical health issues.

**Back problems** are the most common condition, followed by **high blood pressure** and **arthritis**.

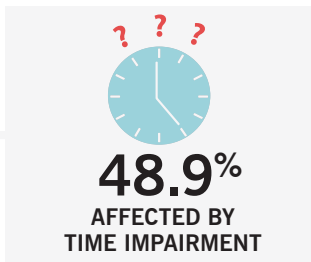
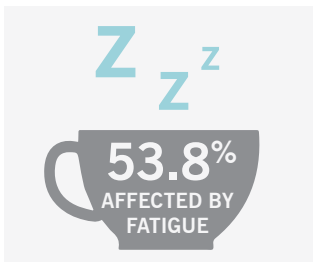
**70%**  
OF CARERS  
LIVE WITH  
CHRONIC  
CONDITIONS  
THEMSELVES



As a result of their role, **carers experience various medical/physical challenges** for which they would seek medical advice.

The most common challenges were **fatigue**, **time management impairment** (lack of time for self-care) or **sleeplessness**.

**CARERS  
EXPERIENCE  
VARIOUS MEDICAL/  
PHYSICAL  
CHALLENGES**



# RESULTS

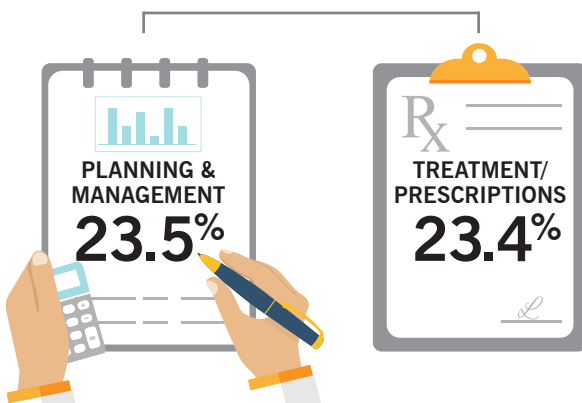
## ► Financial challenges

Financial challenges are also quite common, experienced by 68.5% of respondents.



### TWO BIGGEST CHALLENGES

An increased need for **financial planning and management** and the cost of **treatment/prescriptions** are the two biggest financial challenges faced by carers.



A large majority of respondents **do not use any type of support** to manage these financial challenges.

Of those who do, 11.5% get **financial support from the state**, and 9.2% receive help from a **family member**.

### FOR THOSE THAT DID GET FINANCIAL SUPPORT

**62.9%**  
DID NOT GET  
FINANCIAL SUPPORT



**11.5%**  
SUPPORT FROM  
THE STATE



**9.2%**  
SUPPORT FROM  
A FAMILY MEMBER





# RESULTS

## ► Information support

**65.8%**

GET INFO FROM THE INTERNET

Carers mostly use the internet to get information.



**42.1%**

GET INFO FROM PARKINSON'S ASSOCIATIONS

Parkinson's associations are used as a source of information by 42.1% of respondents.

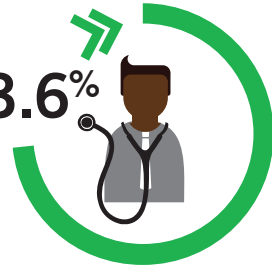
**30.3%**

SAID THEY USED



=  
AS AN INFORMATION TOOL

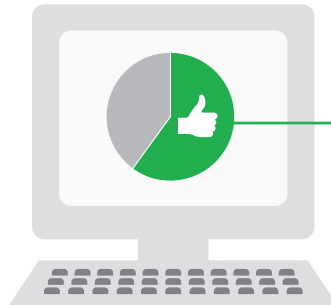
**73.6%**



SAID HEALTHCARE PROFESSIONALS' INFORMATION WAS USEFUL OR VERY USEFUL

Only **30.3%** of respondents answered that they use discussions with **healthcare professionals** as an informational tool. However, those that have these discussions consider them to be the **most impactful information support tool**; **73.6%** rank them as being either **useful** or **very useful**.

By comparison, the internet, **the most commonly used source of information**, was judged either useful or very useful by **60.2%**.



INFORMATION FROM THE INTERNET WAS SEEN AS USEFUL OR VERY USEFUL BY

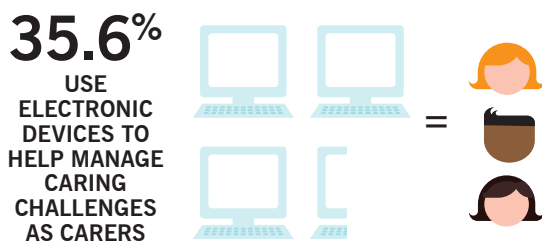
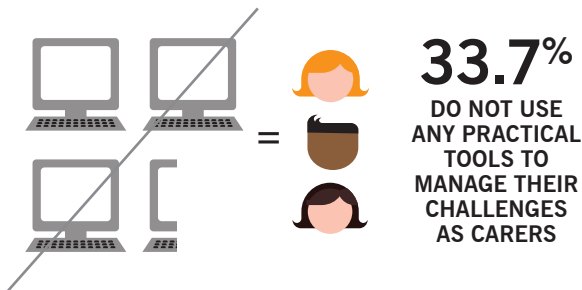
**60.2%**

# RESULTS

## Information support

A **third** of respondents do not use any practical tools to manage their challenges as a carer.

**Electronic devices (computer, smartphone/tablet apps, telemonitoring and e-health systems)** are used by 35.6% of respondents to manage their caring challenges.



**Professional support** for caring is only used by 15% of carers and professional support for household chores by 17.7%, **even though** these support methods are considered the most impactful.



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# ANALYSIS

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In our survey, we found that carers are facing different challenges. Interestingly most of them declared facing at least one medical challenge that could lead them to seek medical assistance.

A vast majority of respondents are living with a chronic condition, which supports Pinquart and Sørensen's<sup>2</sup> cross-sectional analysis that reveals carers are in worse physical and psychological health than non-carers.

Most of the respondents share their home with the people with Parkinson's, which is consistent with Kaschowitz and Brandt's<sup>3</sup> findings that, across Europe, carers inside the household report worse (self-perceived and/or mental) health.

To cope with those issues, carers mostly rely on prescription medicines and medical consultations; this indirectly increases the global cost of Parkinson's management for health systems.

It is interesting to note that from the carer's perspective, the relation with physicians seems to be underutilised, perhaps because there is a perception that physicians are less trained to consider carers than to patients with Parkinson's.

However, it should be noted that several patient associations<sup>4</sup> have developed training programs to help physicians support and guide carers to do their best to cater for their loved ones, while being responsible for their own health too.

Not surprisingly, the emotional, and psychological challenges carers face while taking care of a person with Parkinson's were clearly reported in this study.

Support from family and friends was considered very impactful by our respondents, reinforcing the significance of loneliness that is very common among informal carers<sup>5</sup>.

The need for personal time was also highlighted as an essential way to manage emotional challenges. It confirms the recommendations of Roberts and Struckmeyer<sup>6</sup> on the importance of respite programming.

The many financial challenges encountered by carers can be divided into two major groups: the financial burden of Parkinson's (cost of treatments, transport, homecare, day-care, etc); and the financial burden of the role of carer (loss of income due to time off, unpaid leave or cessation of work to care). The latter also has a negative impact on the health system balance.

According to Marešová et al<sup>7</sup>, the medical and non-medical cost of Parkinson's disease in Europe ranges between €1,949 and

€12,054 per patient per year. Von Campenhausen et al<sup>8</sup> consider that "the economic burden on patients and their families due to PD includes co-payments for medication, special equipment etc. Co-payments comprise up to 5% of total direct costs in the Czech Republic, 6% in Germany and Italy, 8% in Portugal, and 14% in Austria." Co-payments and reimbursement are regulated by each country's healthcare system and so are organized differently across Europe.

This burden is added to the one caused directly by the role of carer. Ciccarelli et al<sup>9</sup> showed that there is a significant and negative effect of daily caring on employment status and work hours.

“There is a perception that physicians are less trained to consider carers than to patients with Parkinson's”

# ANALYSIS



In our survey, respondents ranked the three items corresponding to the financial burden of informal care as having the most impact on their lives.

The support tools carers used varied widely. This is logical considering the many differences between the healthcare and social systems available to support carers in the surveyed

countries. Professional support (be it for caring or for household chores) is deemed to be very useful by respondents, and yet few actually use it. This suggests a future study on the use of professional care to relieve informal carers of people with Parkinson's in Europe – including a deeper analysis of the reasons for not using these services – would be insightful and useful.

<sup>2</sup>Pinquant, M. & Sorensen, S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 18, 250-267 (2003). <sup>3</sup>Kaschowitz, J. & Brandt, M. Health effects of informal caregiving across Europe: A longitudinal approach. *Soc Sci Med* 173, 72-80 (2017). <sup>4</sup>Association, A.M. *Caring for the caregiver : A guide for physicians*. (2018) <sup>5</sup>Beeson, R.A. Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing* 17, 135-143 (2003) <sup>6</sup>Roberts, E. & Struckmeyer, M. The impact of respite programming on caregiver resilience in dementia care : a qualitative examination of family caregiver perspectives. *The journal of healthcare organization, provision and financing* 55(2018) <sup>7</sup>Marešová, P., Klímová, B. & Kuča, K. Medical and non-medical costs of Parkinson disease - comparison of Europe, USA, Asia and Australia. *Čes. slov. Farm* 66, 3-8 (2017) <sup>8</sup>von Campenhausen, S., et al. Costs of illness and care in Parkinson's disease: an evaluation in six countries. *Eur Neuropsychopharmacol* 21, 180-191 (2011) <sup>9</sup>Ciccarelli, N. & Van Soest, A. Informal Caregiving, Employment Status and Work Hours of the 50+ Population in Europe. *De Economist* 166, 363-396 (2018)

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# CONCLUSIONS

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**C**arers of people with Parkinson's face numerous challenges and the support provided by national health systems varies largely from one country to another. The EPDA calls on EU and national policymakers for a holistic approach to Parkinson's management, looking at the impact on the patient, the carer and society at large.

As the number of people with Parkinson's increases, so does the number of carers. As treatments for Parkinson's evolve, allowing patients to remain at home instead of in hospitals or care homes, the increased challenges for the carers of people with Parkinson's cannot be ignored.

It is a public health emergency to find ways to relieve these carers. We need to prevent them from developing health issues and becoming patients themselves.

Patients and carers associations, through surveys like this one, have a part to play to collect data and raise awareness – to help policy makers and healthcare professionals understand the importance of the challenge and to propose new actions.

## The EPDA strongly believes that the EU can make a real difference to the lives of people affected by Parkinson's by:

- addressing the challenges related to **access to medicines, health, and long-term and integrated care, and to home healthcare**
- promoting **research and innovation** activities to provide the Parkinson's community with new treatments and models for adequate care across Europe
- improving **employment conditions, reducing stigma, and ensuring accessibility to essential services** for people with Parkinson's and their carers
- improving **systematic data collection**, by including up-to-date information on Parkinson's in the 'State of Health in Europe' cycle
- considering developing a **model for disease registries** for Parkinson's based on existing good practices at national and regional level
- exploring the possibility of creating **European Reference Networks (ERNs)**, with specific regards to rare forms and advanced stages of Parkinson's
- providing **funding** for projects that improve the quality of life of people with Parkinson's and their families
- raising awareness and proposing tangible solutions about the specific issues and challenges facing people with **young-onset Parkinson's** throughout Europe, to preserve their quality of life especially in relation to **working life and family**
- raising awareness and proposing tangible solutions about the challenges facing **carers** of people with Parkinson's in Europe, to preserve their quality of life.

# ACKNOWLEDGEMENTS

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Thanks to Dr H el ene Rossinot, Prof Pablo Martinez-Martin, Prof Per Odin, Prof K Ray Chaudhuri, Dr Catherine Billo et and former EPDA Vice-President Susanna Lindvall for their invaluable scientific support throughout this project.

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Danny Lavender MBE (UK)

Eleonor H ogstr om (Sweden)

Florence Delamoye (France)

Francesco De Renzis (Italy)

Ivona  udova (Czech Republic)

Josefa Domingos (Portugal)

Jutta Ahmerkamp-B ohme (Germany)

Linda Lombi (Italy)

Lizzie Graham (UK)

Ola Larsson (Sweden)

Patricia P erez (Spain)

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Pieter Philipsen (Belgium)

Russell Patten (Belgium)

**Special thanks to all the carers who took part in interviews to help us design this survey and to all the Parkinson's associations who collaborated in finding them, helped in promoting the survey and arranged translations:**

Associa o Portuguesa de Doentes de Parkinson (Portugal)

Beat Parkinson's (UK)

Društvo Trepetlika (Slovenia)

Federaci n Espa ola de Parkinson (Spain)

France Parkinson (France)

Grayling (Belgium)

Jung und Parkinson (Germany)

Krakowskie Stowarzyszenie Os b Dotknionych Chorob Parkinsona (Poland)

Malta Parkinson's Disease Association (Malta)

Parkinson Italia (Italy)

Parkinson Vereniging (The Netherlands)

ParkinsonF rbundet (Sweden)

Parkinsonforeningen (Denmark)

Parkinson-liitto ry (Finland)

Parkinson's Association of Ireland (Ireland)

Spole nost Parkinson, z.s. (Czech Republic)

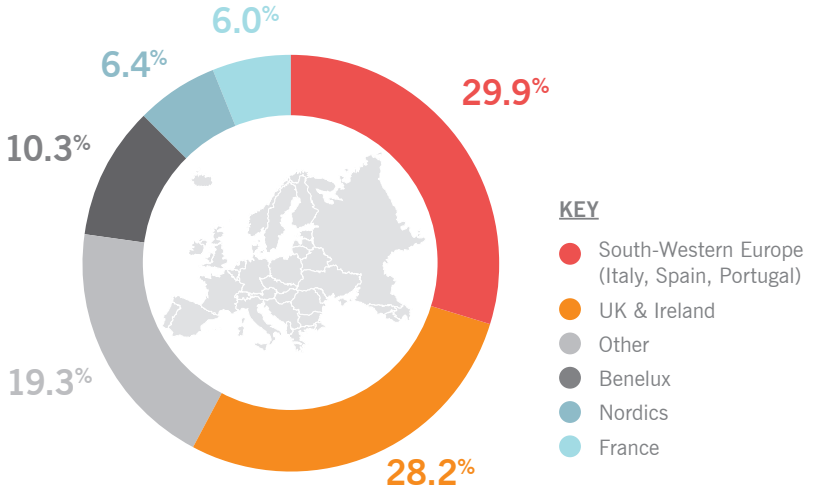
Vlaamse Parkinson Liga vzw (Belgium)

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# ANNEX – GRAPHS

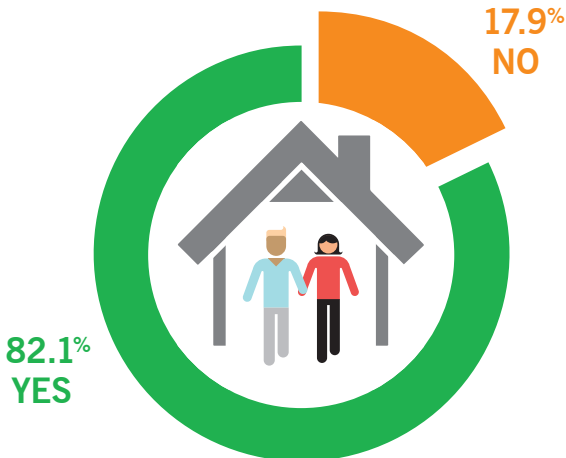
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▶ **1. Which country do you live in?**



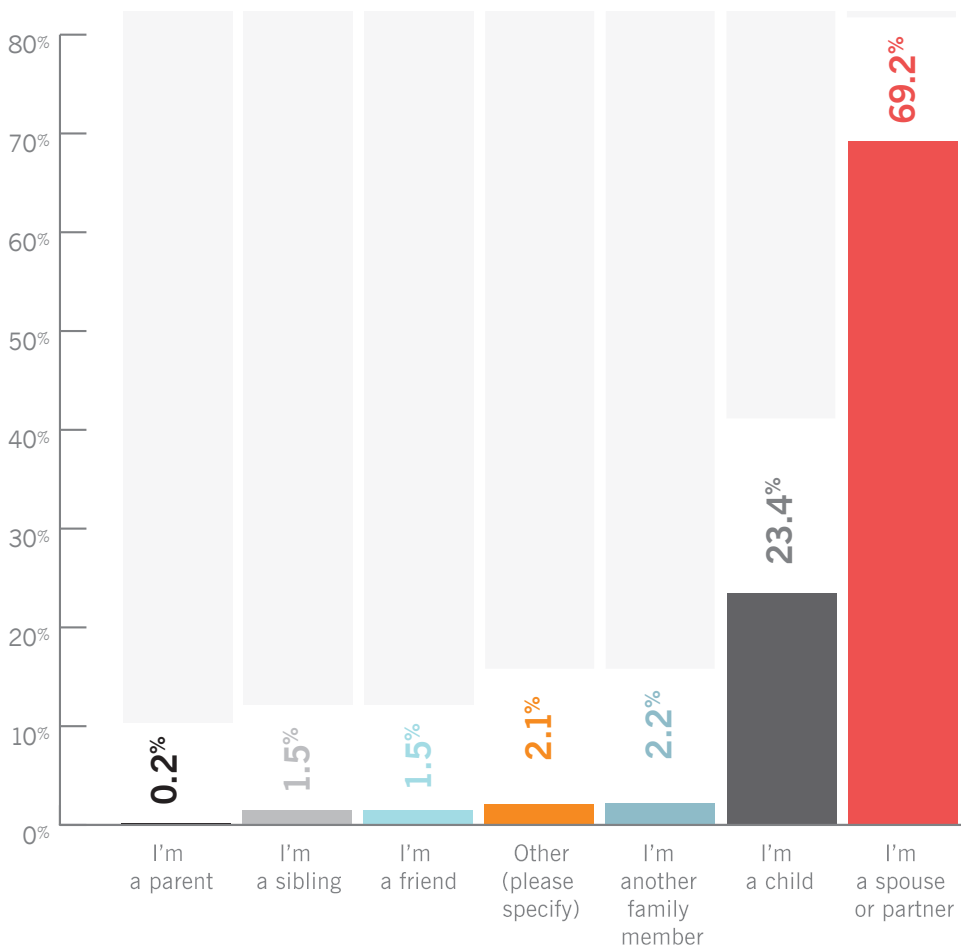
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▶ **2. Do you live with the person you care for?**



# ANNEX – GRAPHS

## ▶ 3. What is your relationship to the person you care for?



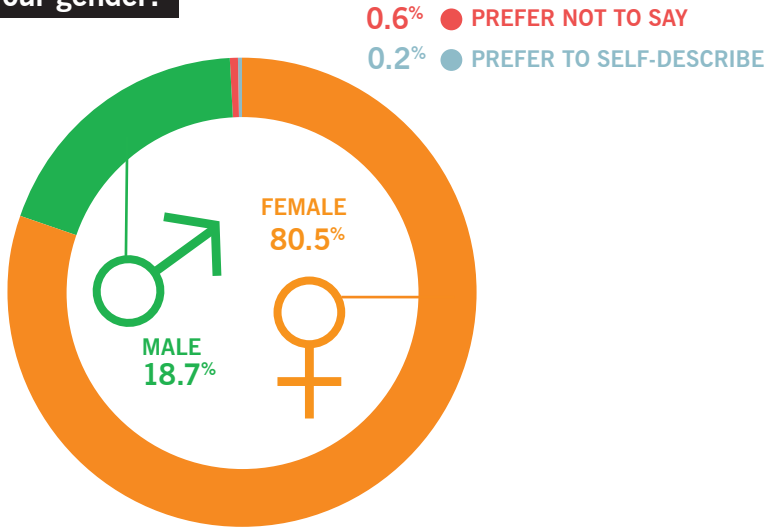


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# ANNEX – GRAPHS

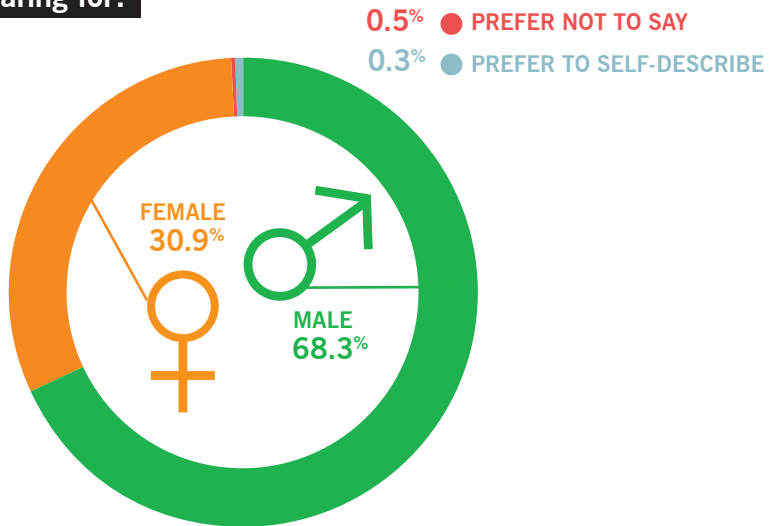
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▶ **4. What is your gender?**



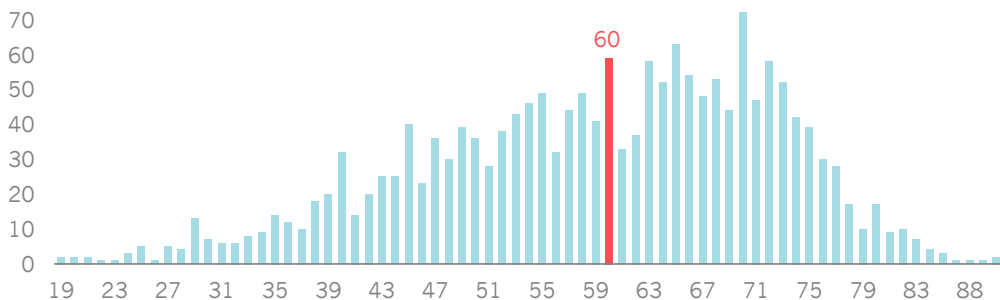
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▶ **5. What is the gender of the person with Parkinson's you are caring for?**

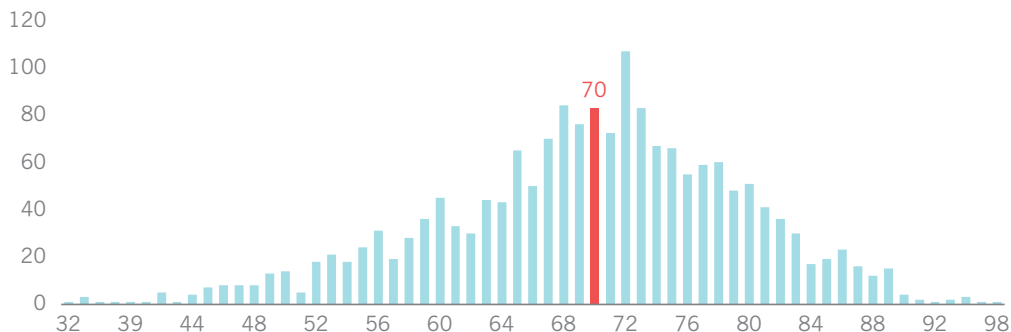


# ANNEX – GRAPHS

## ▶ 6. How old are you?

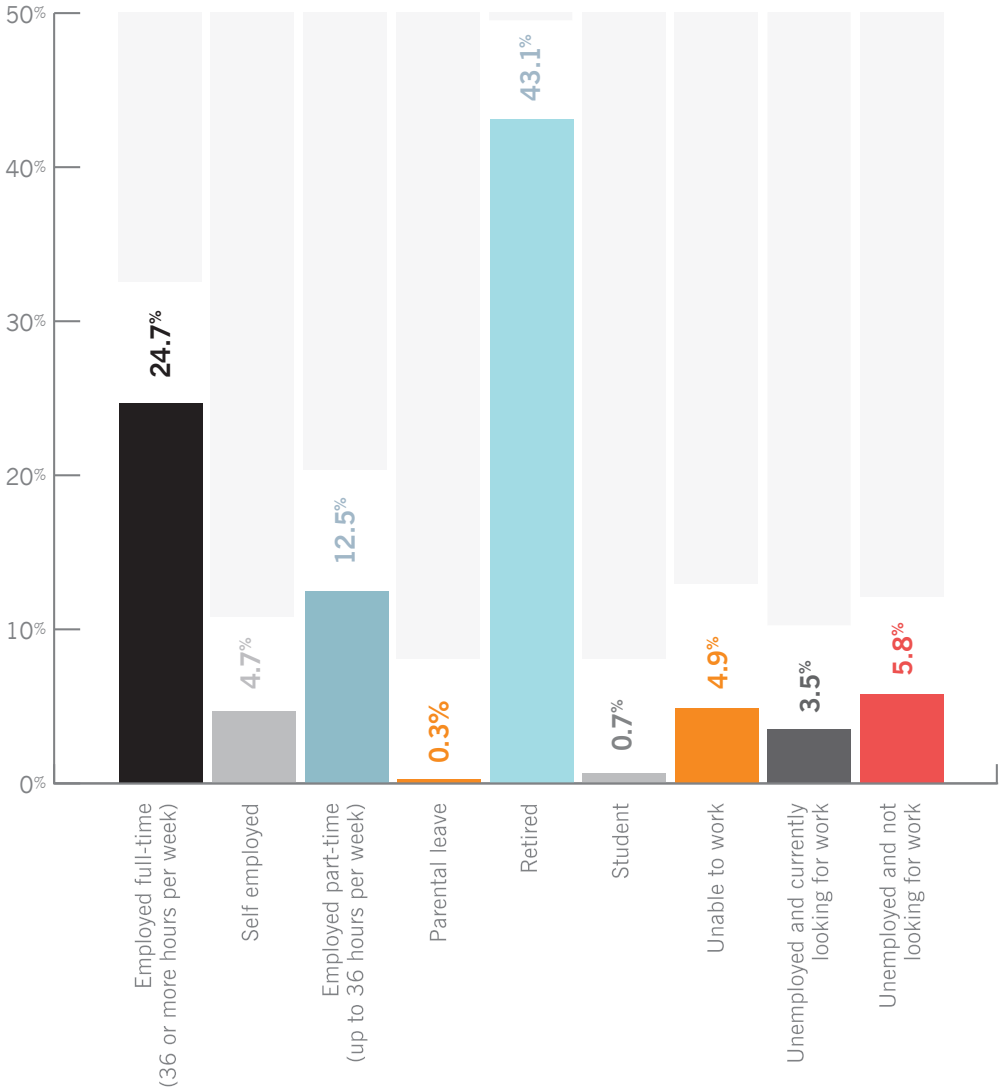


## ▶ 7. How old is the person with Parkinson's you are caring for?



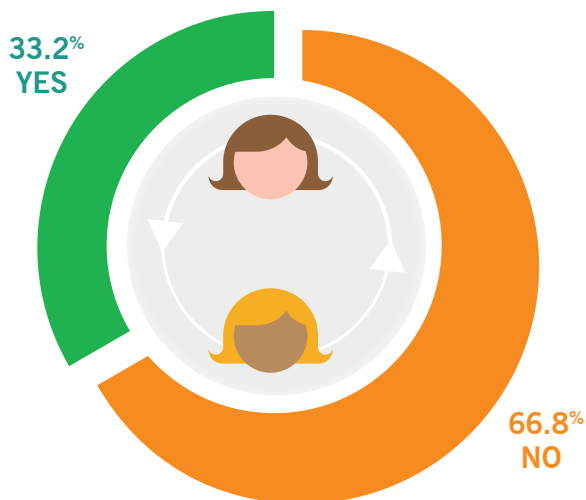
# ANNEX – GRAPHS

## 8. What is your current employment status?

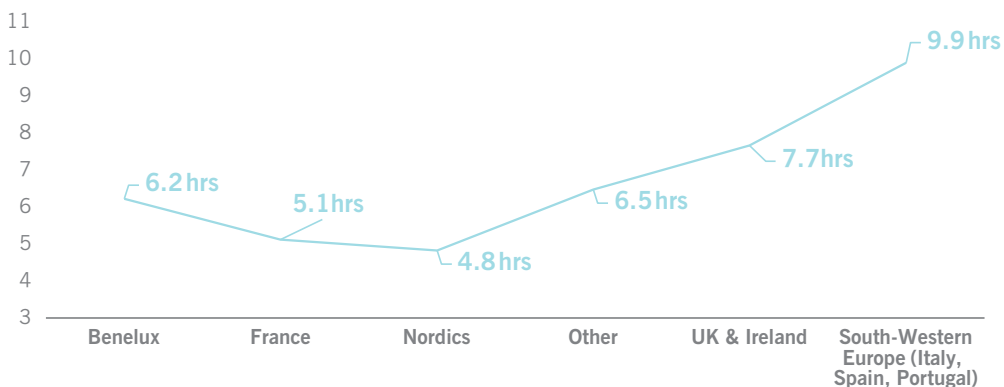


# ANNEX – GRAPHS

## ▶ 9. Do you share caring for this person with someone else?

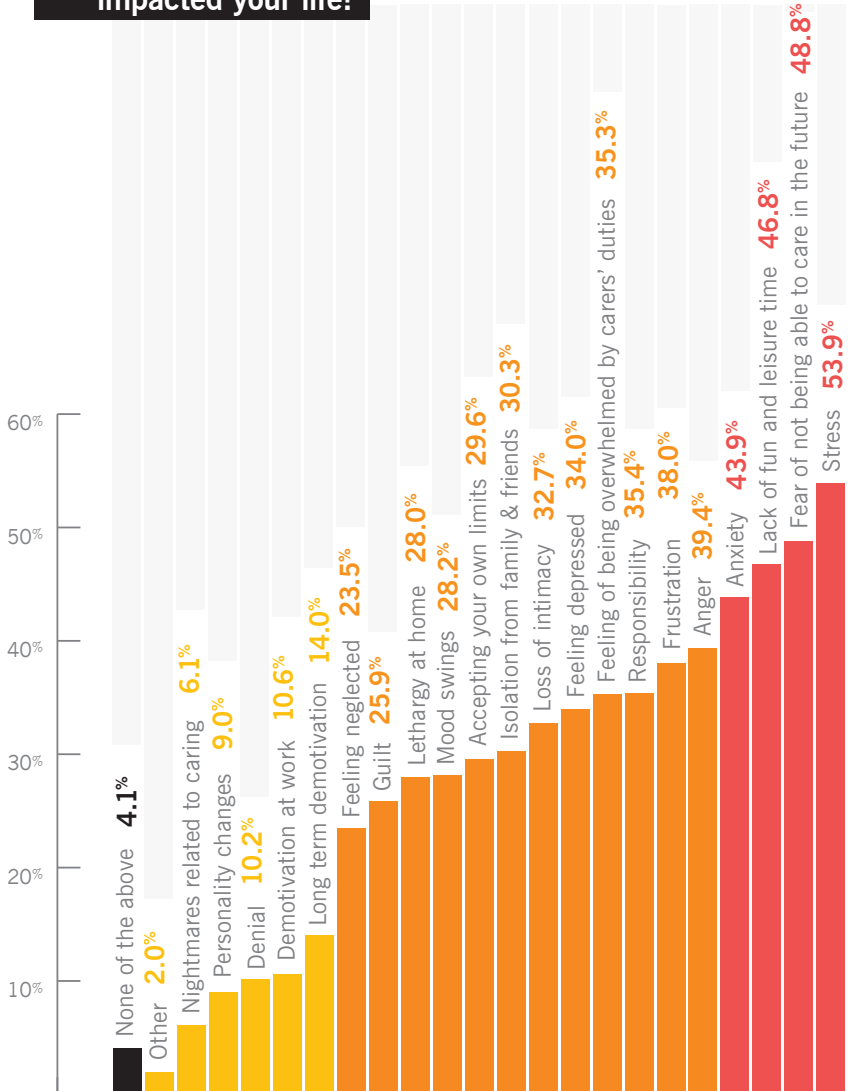


## ▶ 10. On average, how many hours per day do you spend on caring tasks?



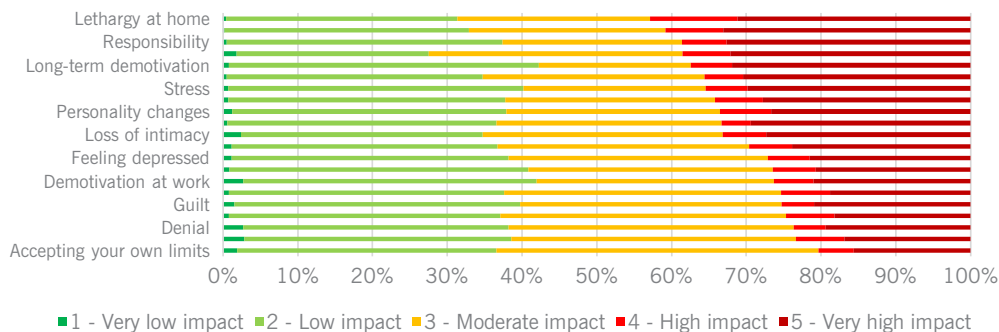
# ANNEX – GRAPHS

## 11. As a result of caring for someone with Parkinson's, have you experienced any emotional challenges that have impacted your life?

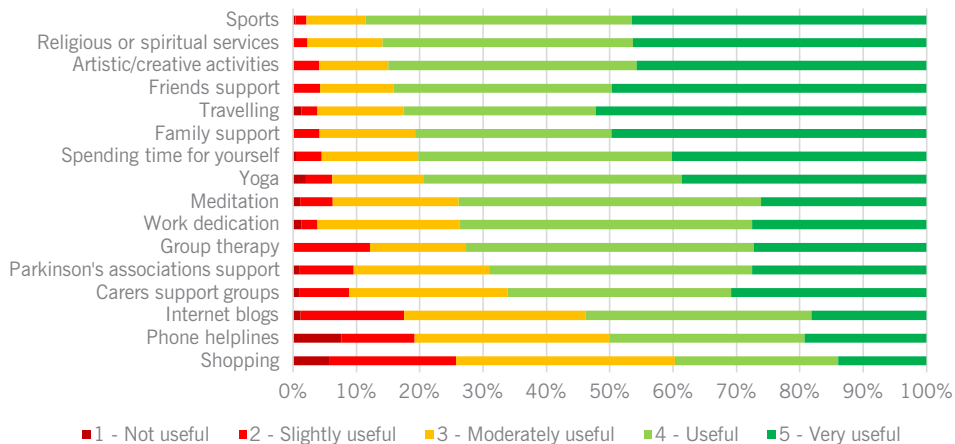


# ANNEX – GRAPHS

## ▶ 12. On a scale of 1-5, how big an impact do these challenges have on you?



## ▶ 13. On a scale of 1-5, how useful are these support tools for you?



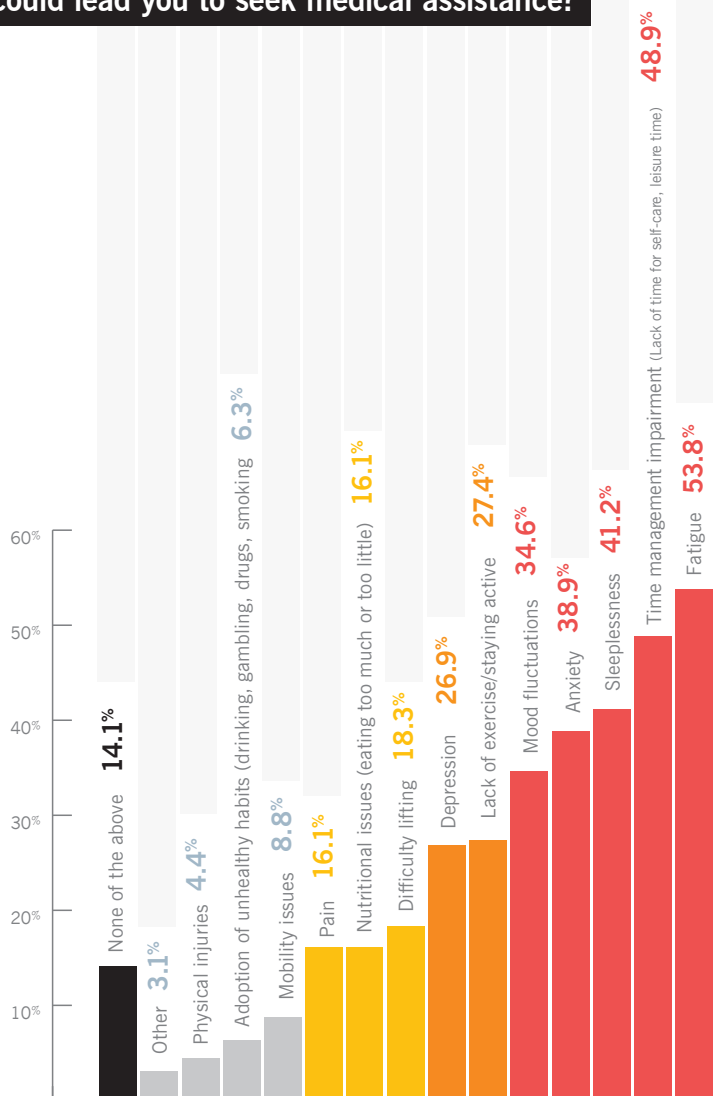
# ANNEX – GRAPHS

## ▶ 14. Do you personally live with any of the following chronic conditions?

	Benelux	France	Nordics	Other	South-Western Europe (Italy, Spain, Portugal)	UK & Ireland	Grand total
History of stroke	2%	3%	2%	2%	1%	3%	2%
Diabetes	6%	5%	7%	8%	4%	3%	5%
Heart disease	9%	9%	2%	8%	7%	3%	6%
Respiratory problems	7%	11%	4%	6%	7%	8%	7%
Irregular heartbeat (Arrhythmia)	5%	7%	6%	7%	11%	5%	7%
Visual impairment	4%	13%	5%	9%	13%	4%	8%
Hearing impairment	10%	11%	13%	12%	10%	10%	10%
High cholesterol	14%	11%	14%	18%	19%	15%	16%
Arthritis	11%	18%	15%	18%	11%	26%	17%
Other (please specify)	23%	21%	18%	22%	20%	19%	20%
High blood pressure	22%	18%	20%	25%	20%	23%	22%
Back problems	23%	39%	30%	36%	47%	26%	35%
No (I don't live with any of these conditions)	32%	30%	34%	24%	23%	32%	28%

# ANNEX – GRAPHS

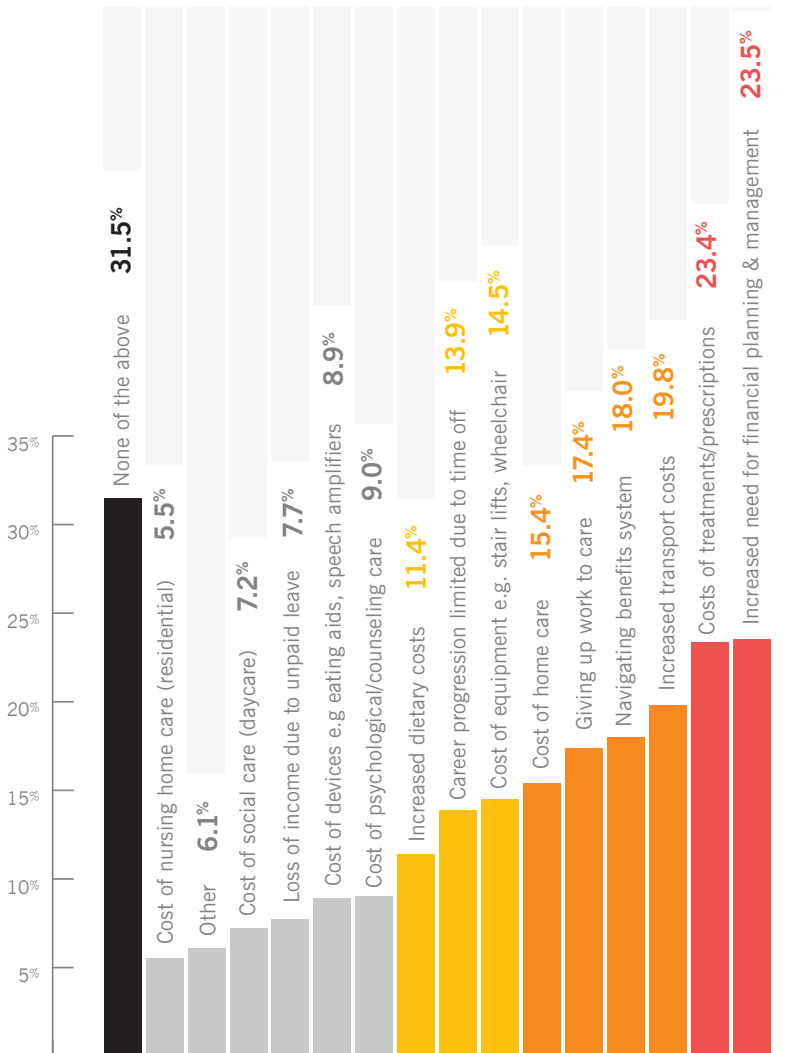
15. As a result of caring for someone with Parkinson's, have you experienced any physical/medical challenges that could lead you to seek medical assistance?





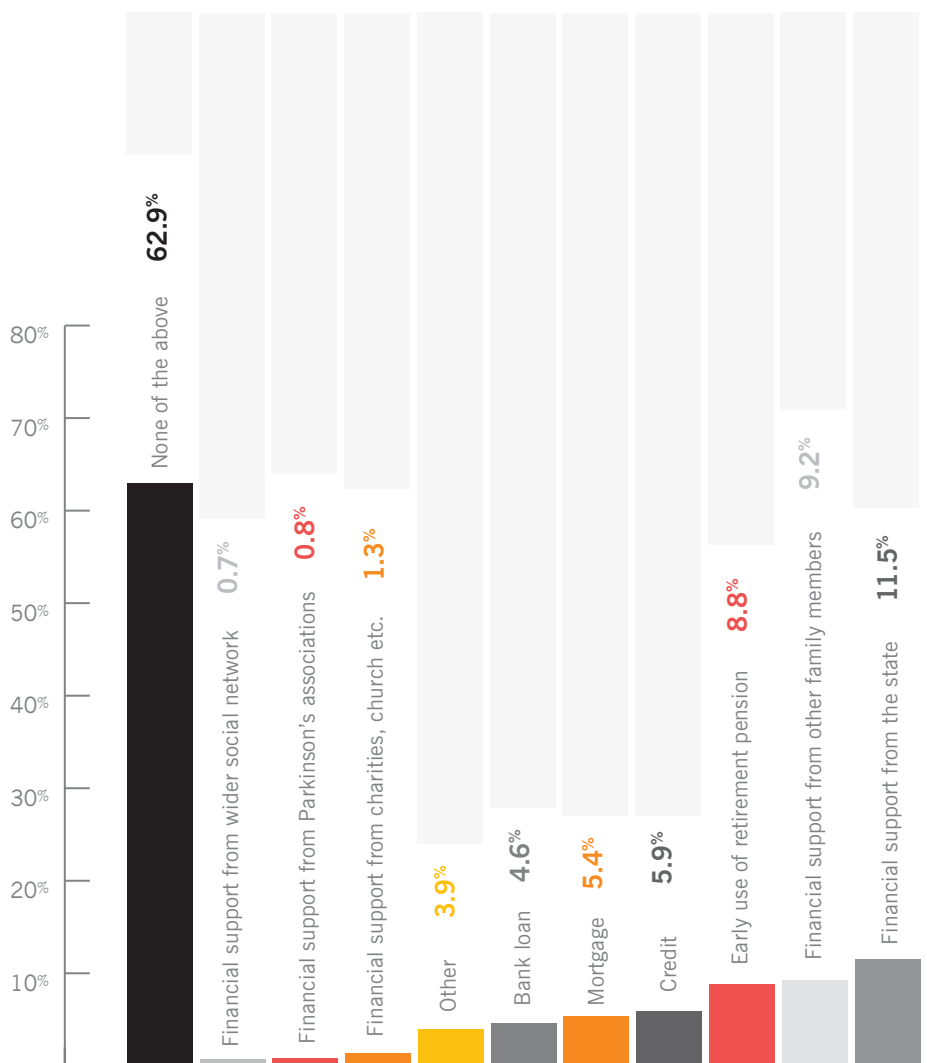
# ANNEX – GRAPHS

## ▶ 16. As a result of caring for someone with Parkinson’s, have you experienced any financial challenges that have impacted your life?



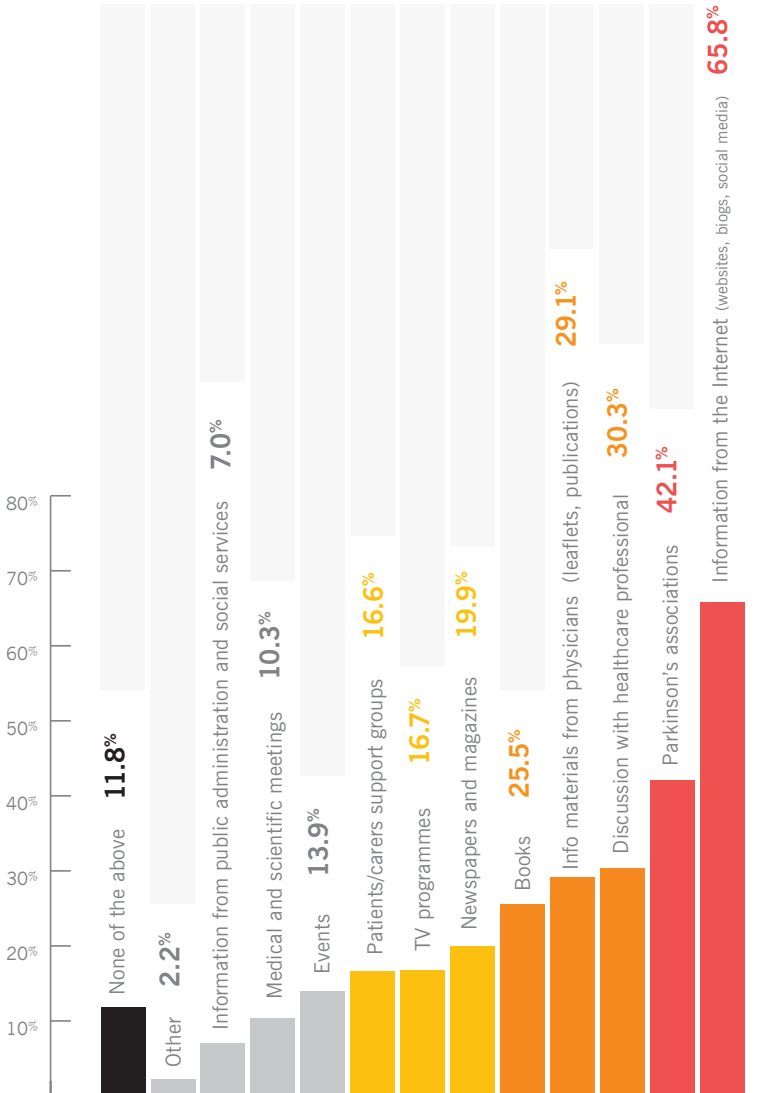
# ANNEX – GRAPHS

▶ **17. Please indicate if you are using any types of support listed below to manage your financial challenges**



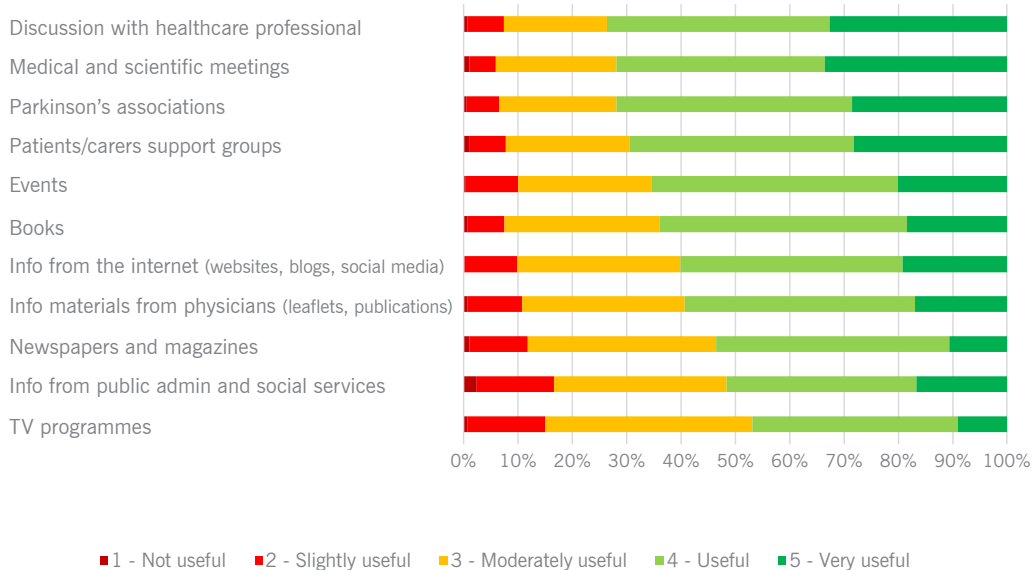
# ANNEX – GRAPHS

## 18. Please indicate if you are using any types of informational support listed below to manage your challenges as a carer



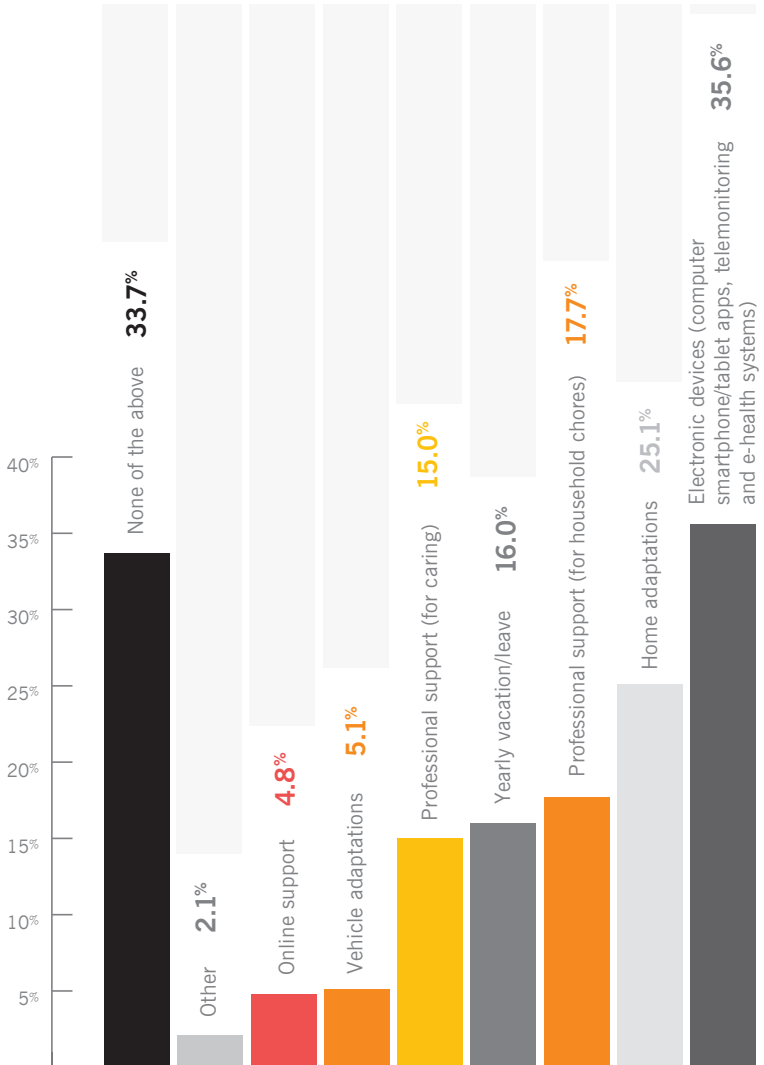
# ANNEX – GRAPHS

## ▶ 19. On a scale of 1-5, how useful are these support tools for you?



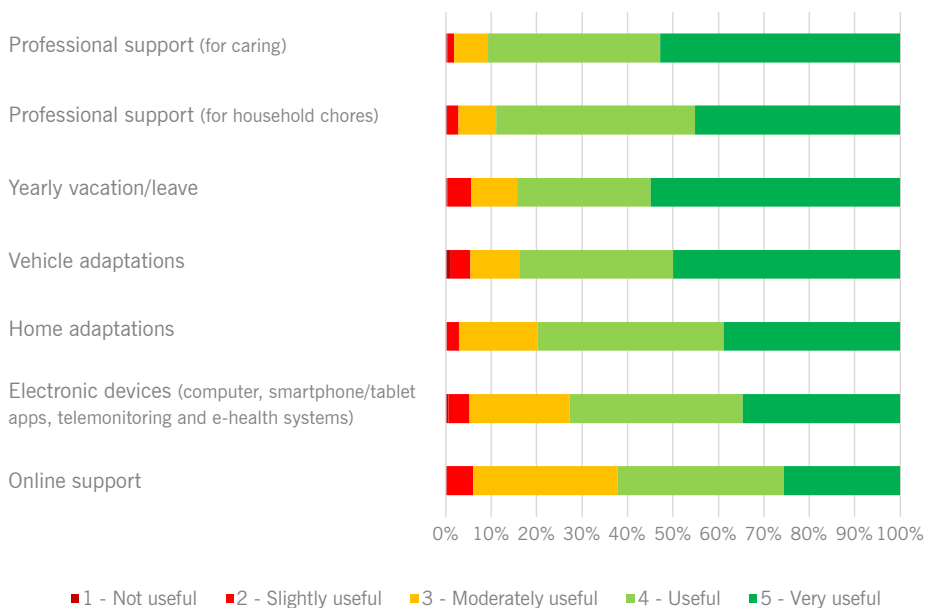
# ANNEX – GRAPHS

## ▶ 20. Please indicate if you are using any types of practical support listed below to manage your challenges as a carer



# ANNEX – GRAPHS

## ▶ 21. On a scale of 1-5, how useful are these support tools for you?



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