

An EPDA-UCB survey to better understand the challenges of living with Parkinson's.

Final results

October 2018

UCB co-created and financially supported this survey

Introduction

In July 2018 the EPDA, in partnership with long-term industry partner UCB, created a short online survey to better understand some of the issues people with Parkinson's and their families/carers across Europe face on a daily basis.

Goals

We hoped to gain unique insights from the Parkinson's community, that would help us understand:

- how to meet a person with Parkinson's individual needs in a tailored and holistic way, enabling them to live a full life
- how to help people with Parkinson's find appropriate support, and to feel reassured, confident and better able to cope with everyday challenges
- how to enable people living with Parkinson's and their families/carers to maintain their respective identities and to live a full life.

About this report

This report includes two sets of analysis:

Multiple choice responses (compiled by UCB): p11-30

Free text responses (compiled by the EPDA): p32-40

Respondents were asked to answer a set of open questions about their Parkinson's, in a maximum of 100 words

Acknowledgement

The EPDA would like to thank UCB for its extensive support throughout the entire data collection project.

Topline overview (October 2018)

Total responses: 2,001

Full responses 984

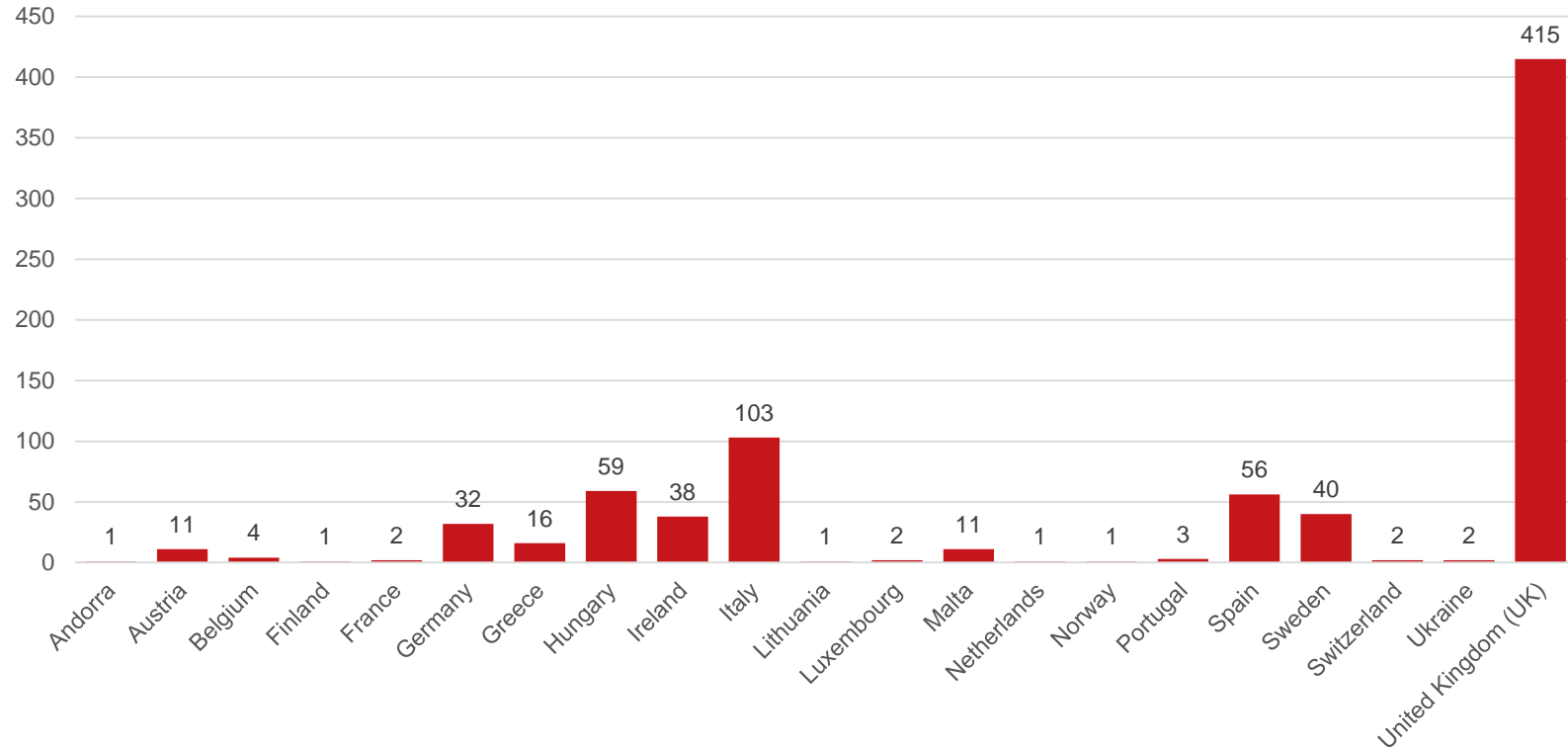
Incomplete responses: 1,017

"Full responses" refers to those participants who responded to the whole survey until the end, but they may have not answered all the questions.

"Incomplete responses" refers to those participants who started the survey, but stopped part way through.

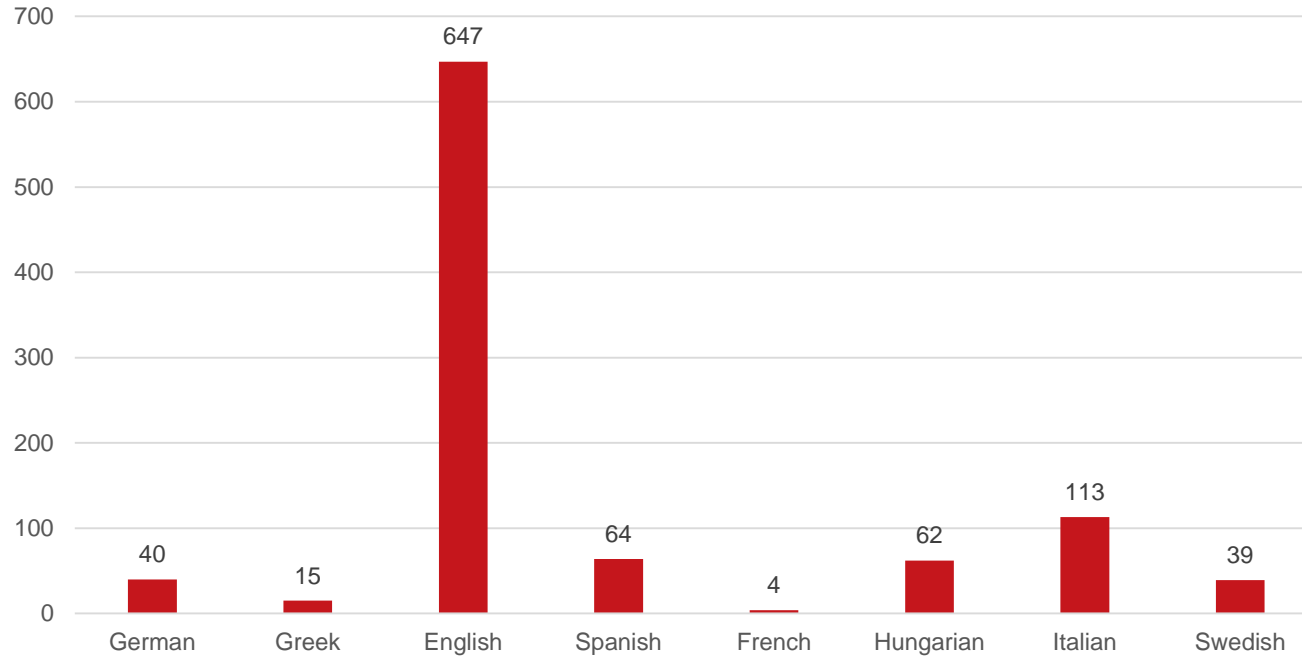
Demographics overview (p6-9)

*Country distribution

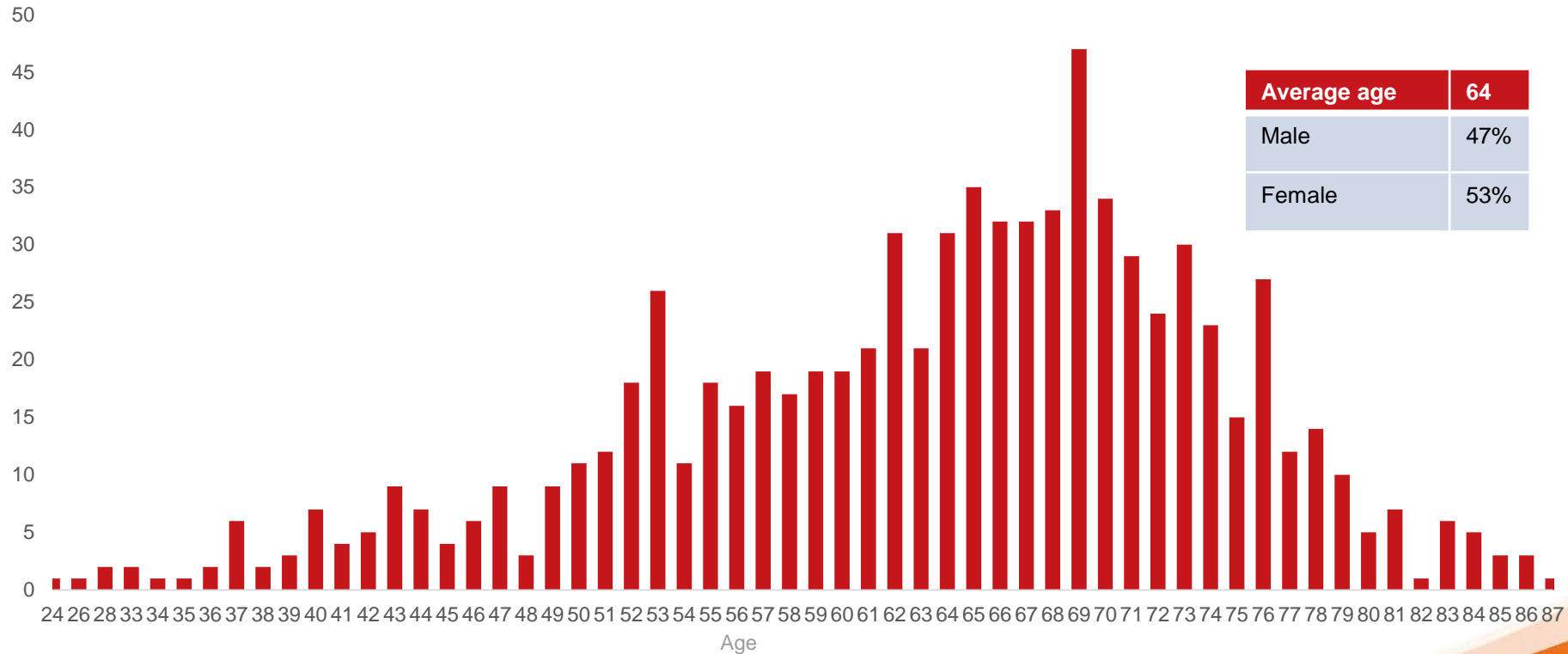


*801 participants completed this question from the 984 full responders

Language distribution

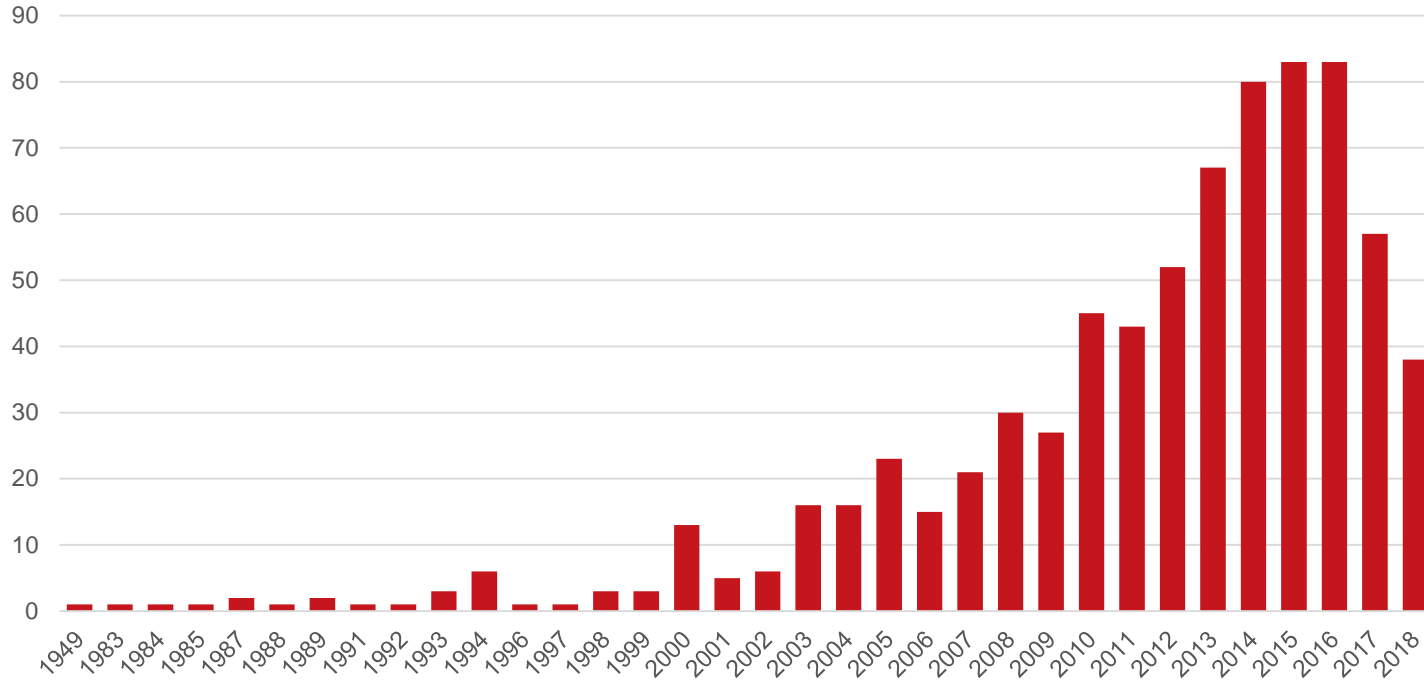


*Age distribution



*802 participants completed this question from the 984 full responders

*Year of diagnosis



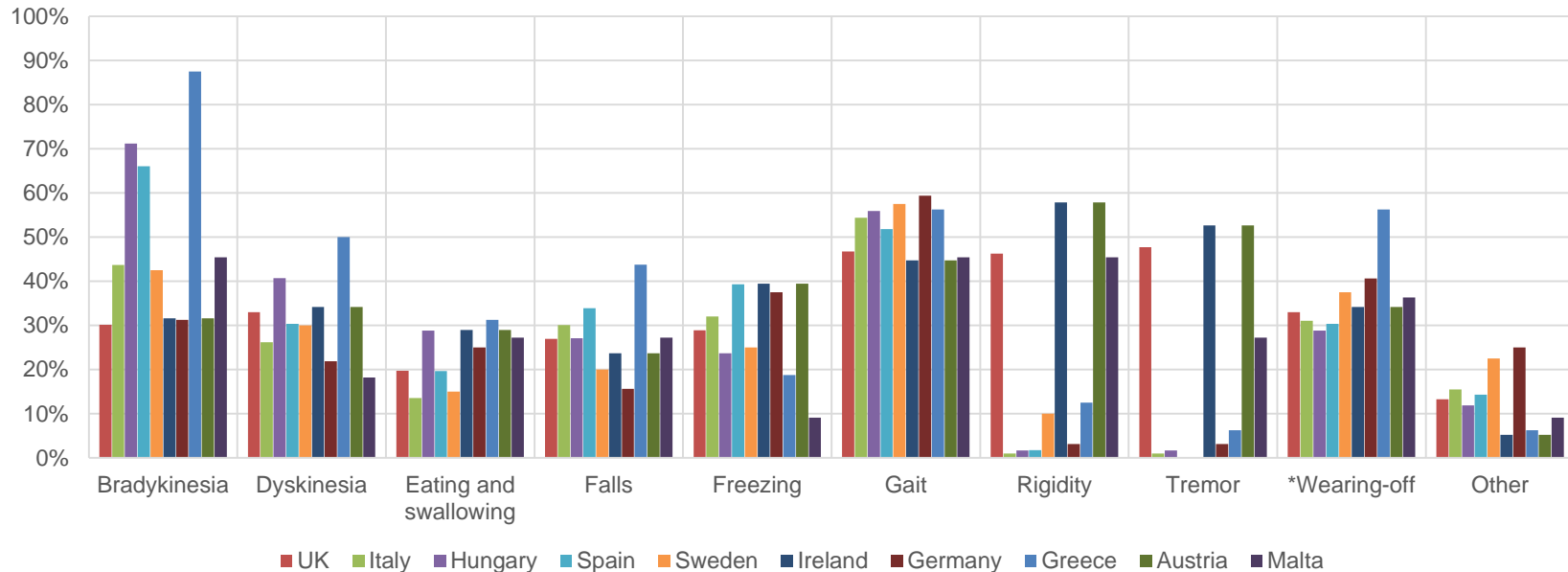
*749 participants completed this question from the 984 full responders

Key themes by country (p11-16)

All full responses (984)

From the list below, please indicate which are the most difficult symptoms and demanding challenges caused by Parkinson's

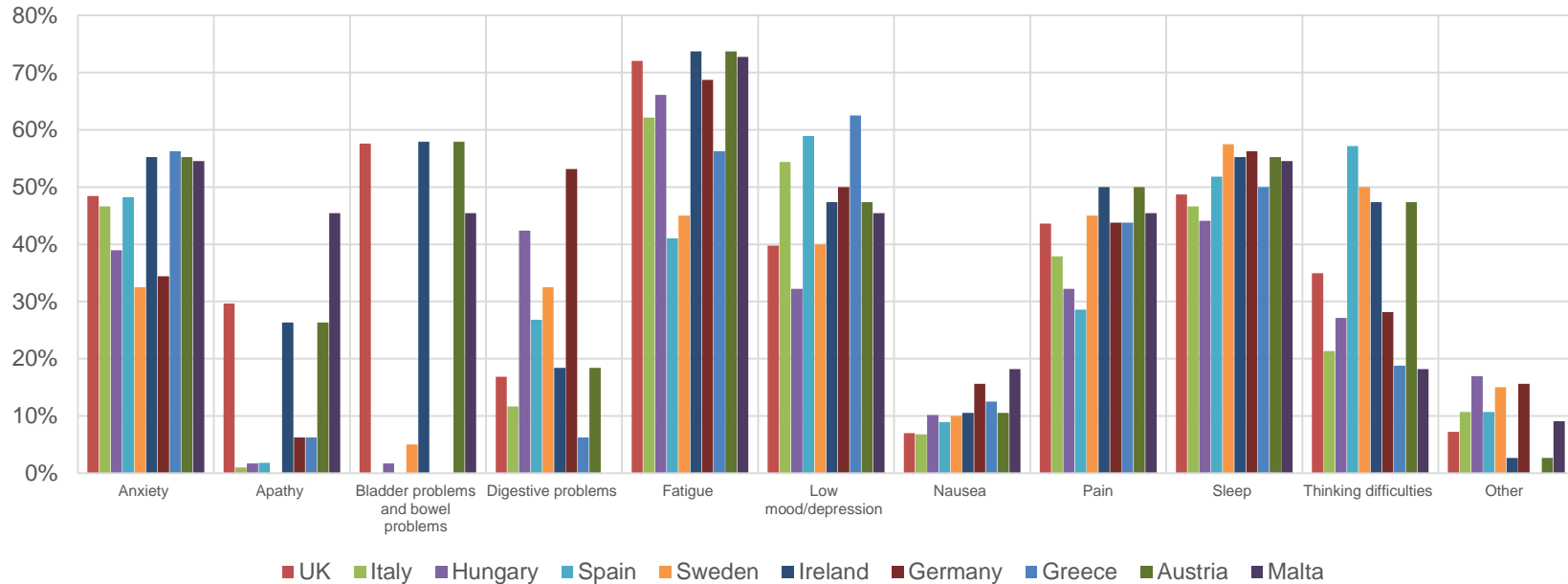
Motor Symptoms



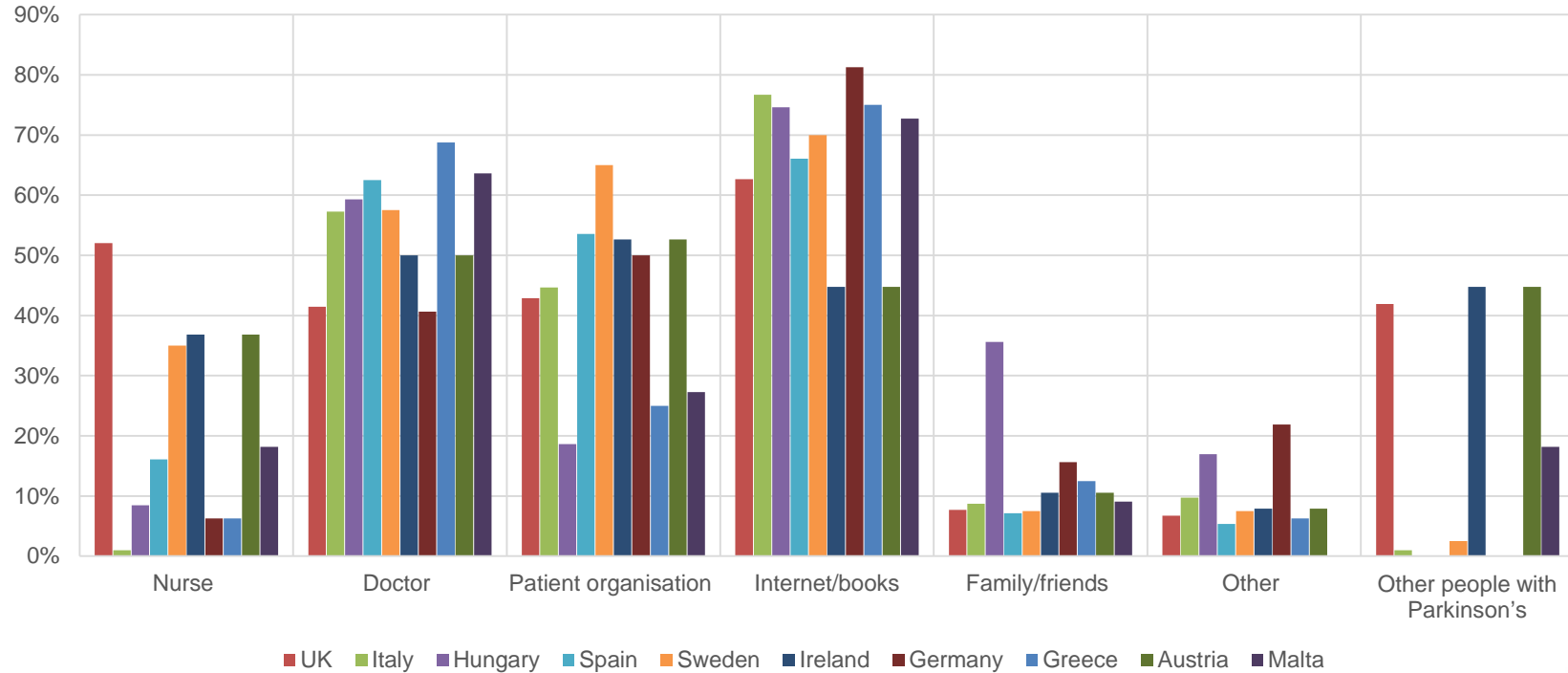
*Wearing-off listed as a Motor Symptom on the EPDA website

From the list below, please indicate which are the most difficult symptoms and demanding challenges caused by Parkinson's

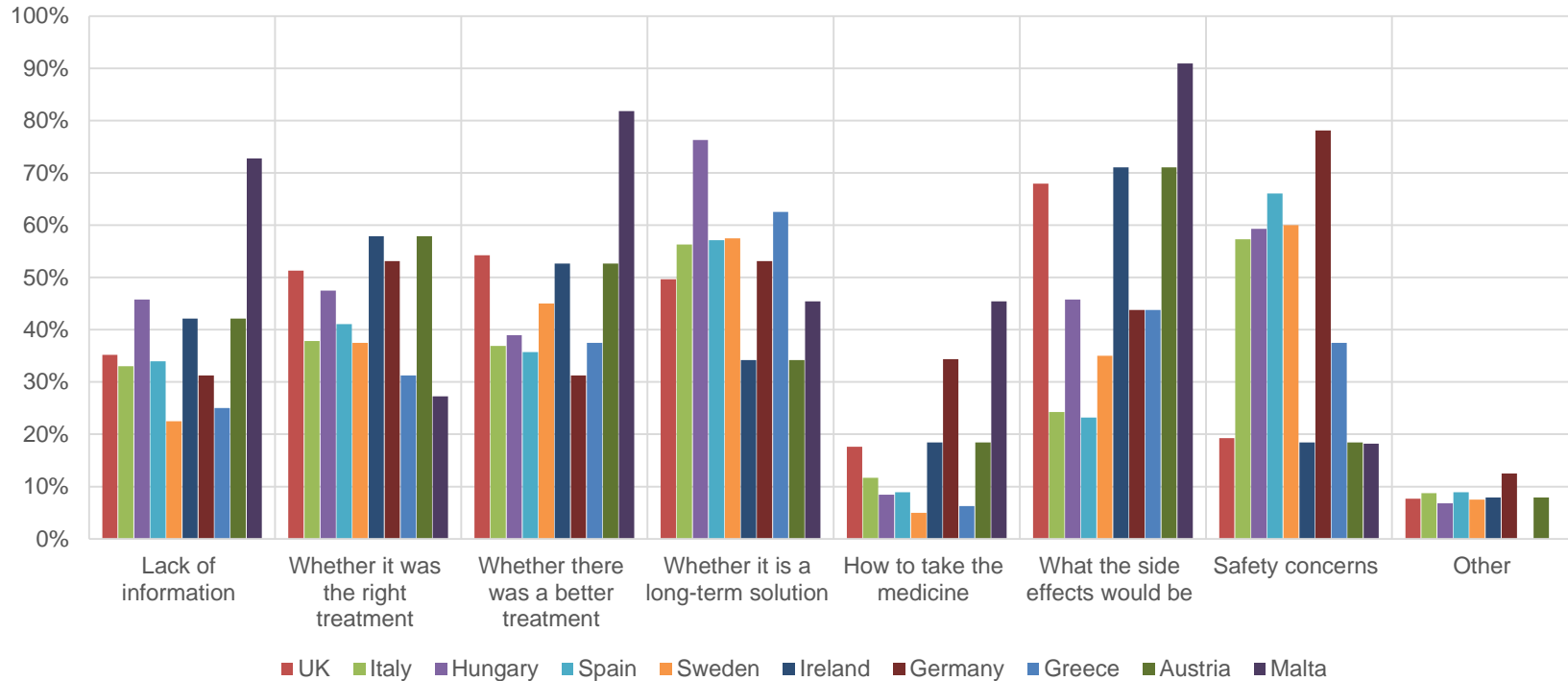
Non-motor symptoms



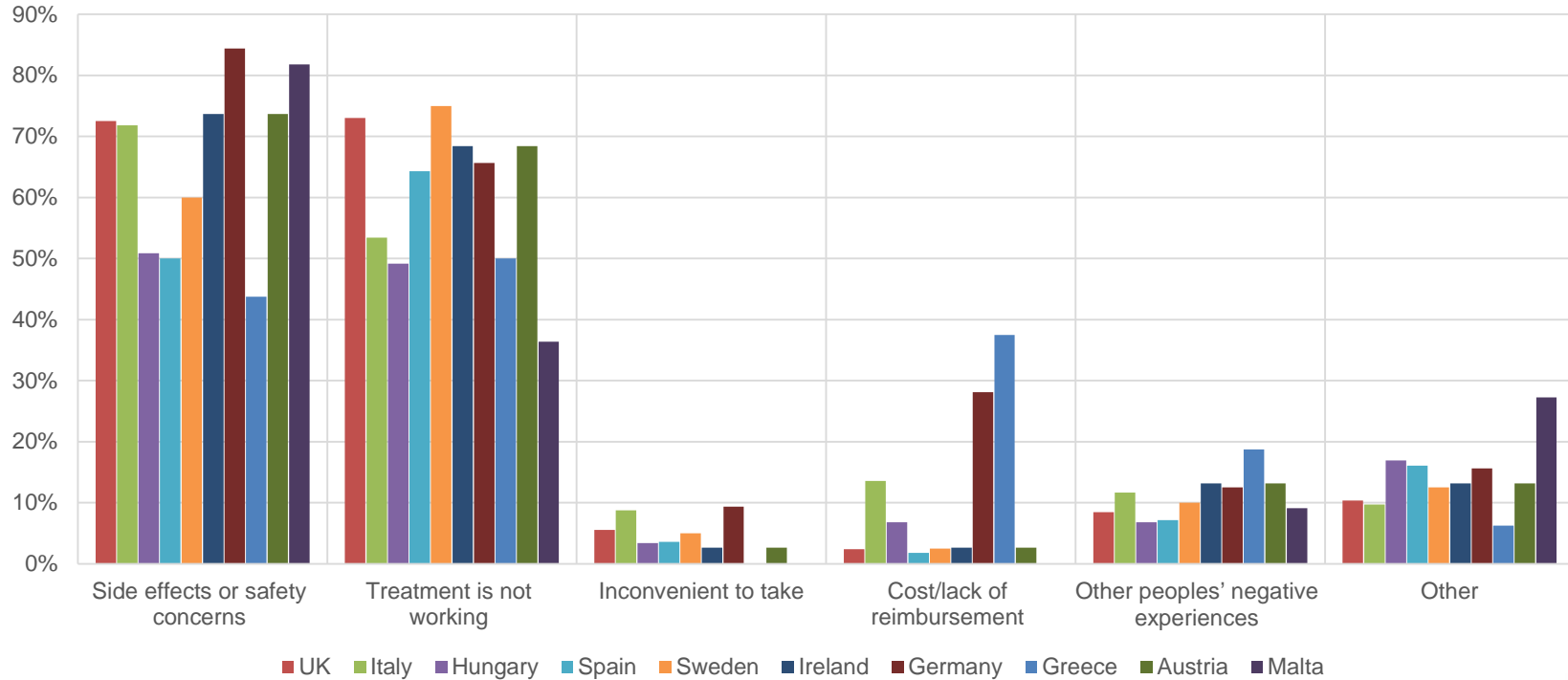
What are the most reliable sources of information?



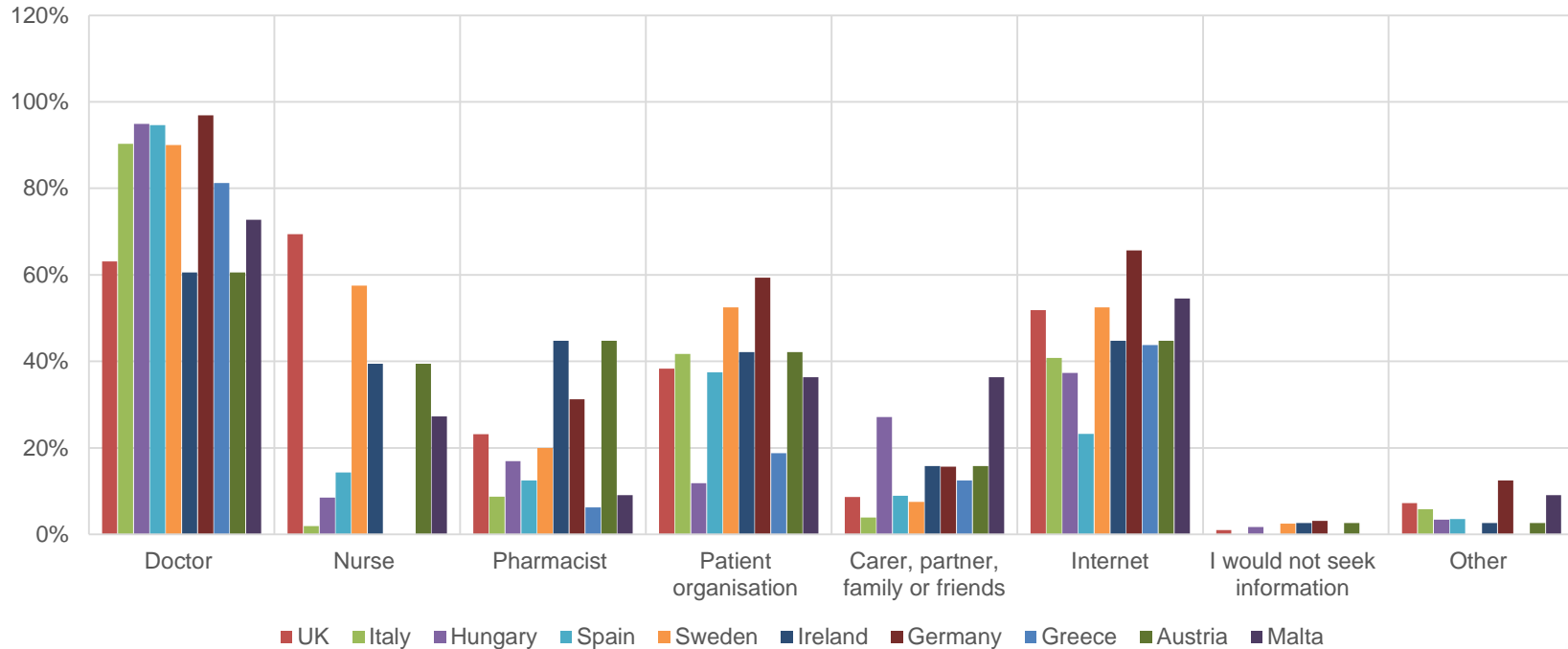
What were your major concerns when the Parkinson's treatment began?



What would be the main reason for stopping a treatment?



If you had problems or questions about Parkinson's medication or treatment, where would you go to seek information to help you?

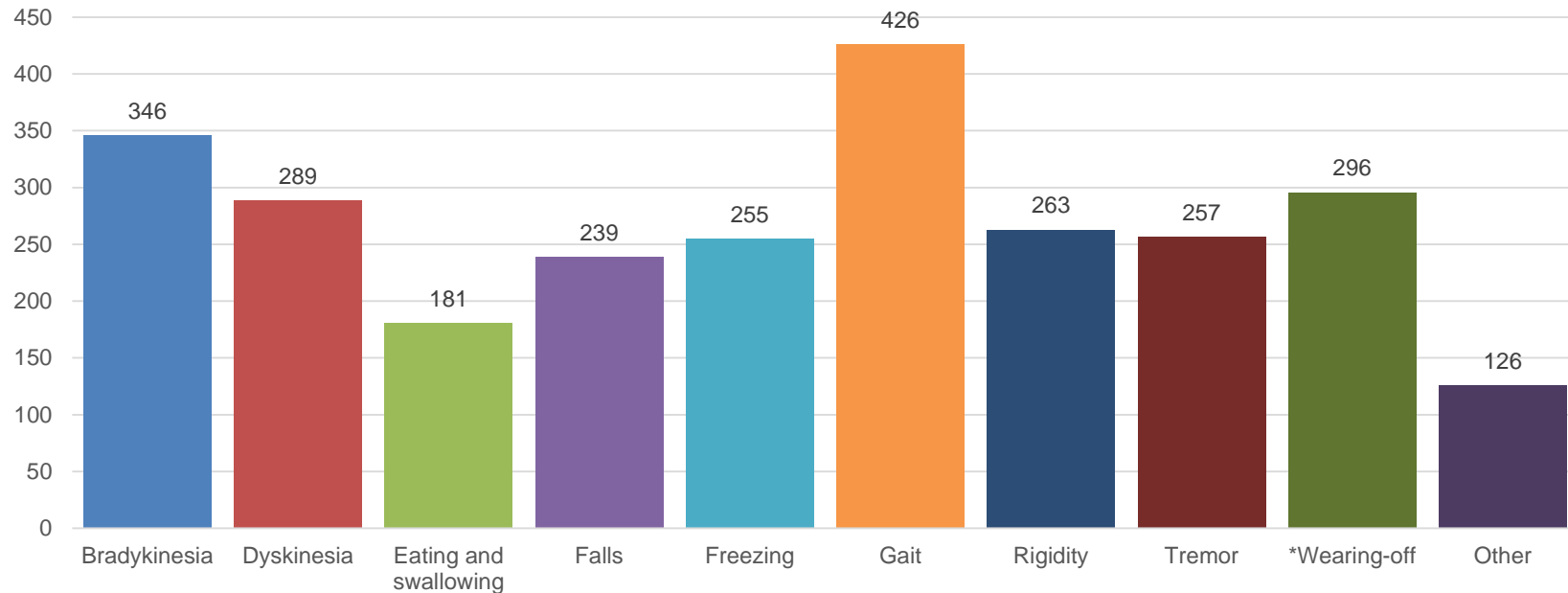


Multiple choice responses, aggregate data for Europe (p18-30)

All full responses (984)

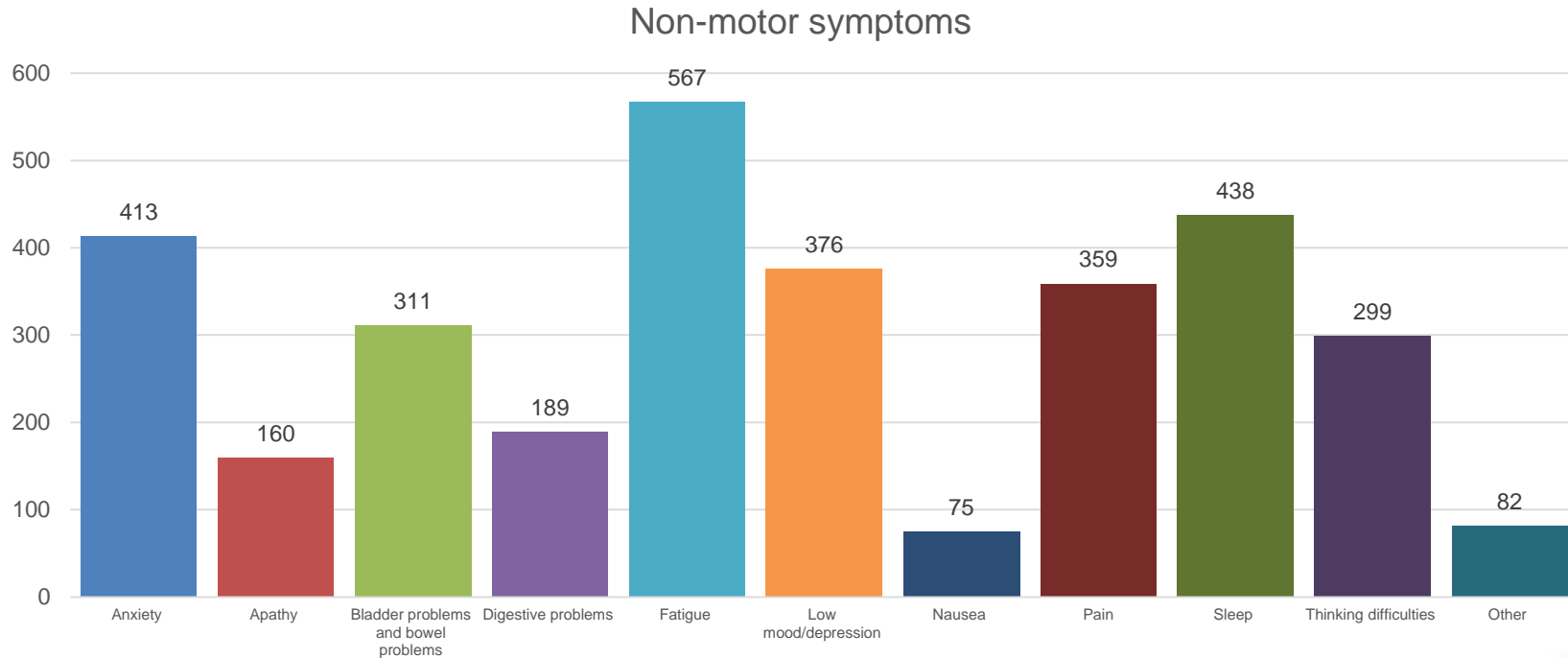
From the list below, please indicate which are the most difficult symptoms and demanding challenges caused by Parkinson's

Motor Symptoms

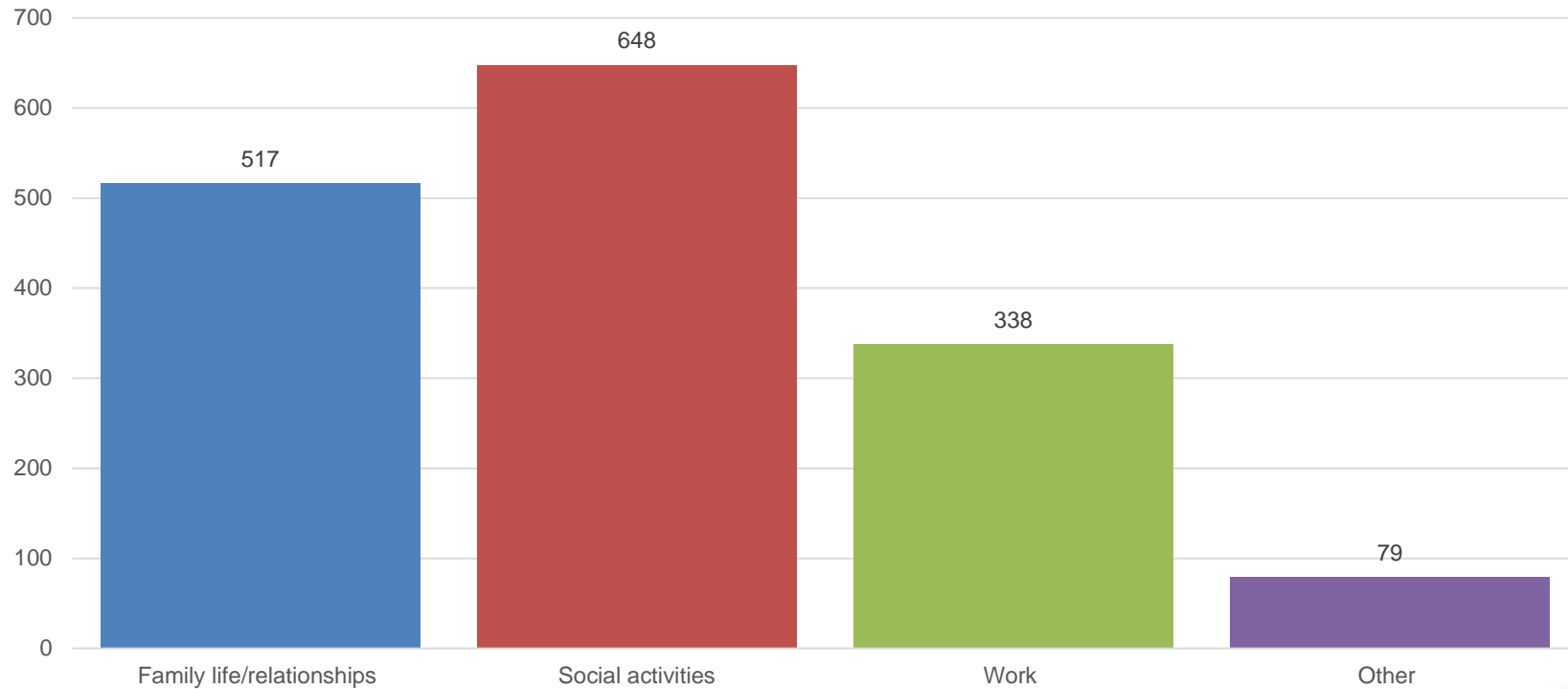


*Wearing-off listed as a Motor Symptom on the EPDA website

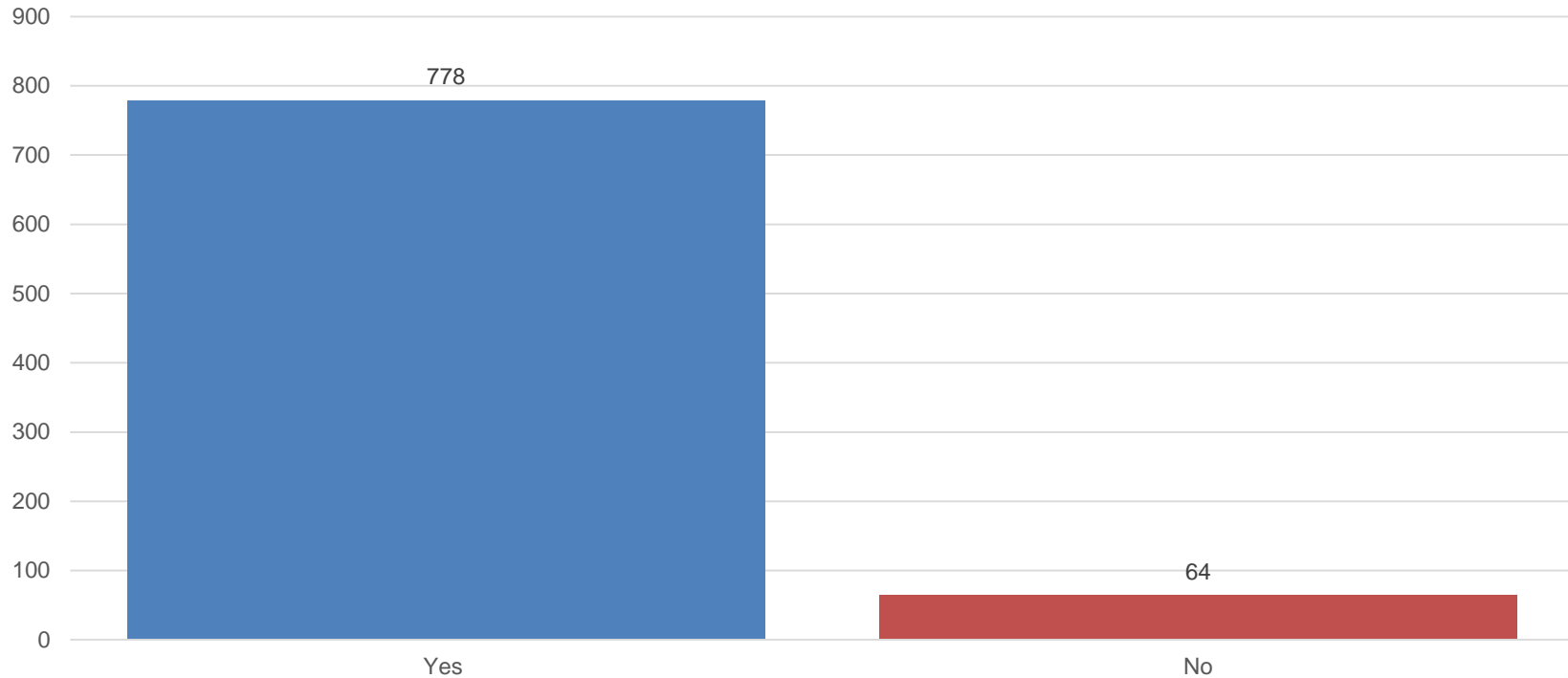
From the list below, please indicate which are the most difficult symptoms and demanding challenges caused by Parkinson's



Which of the following activities are either interrupted or interfered with?

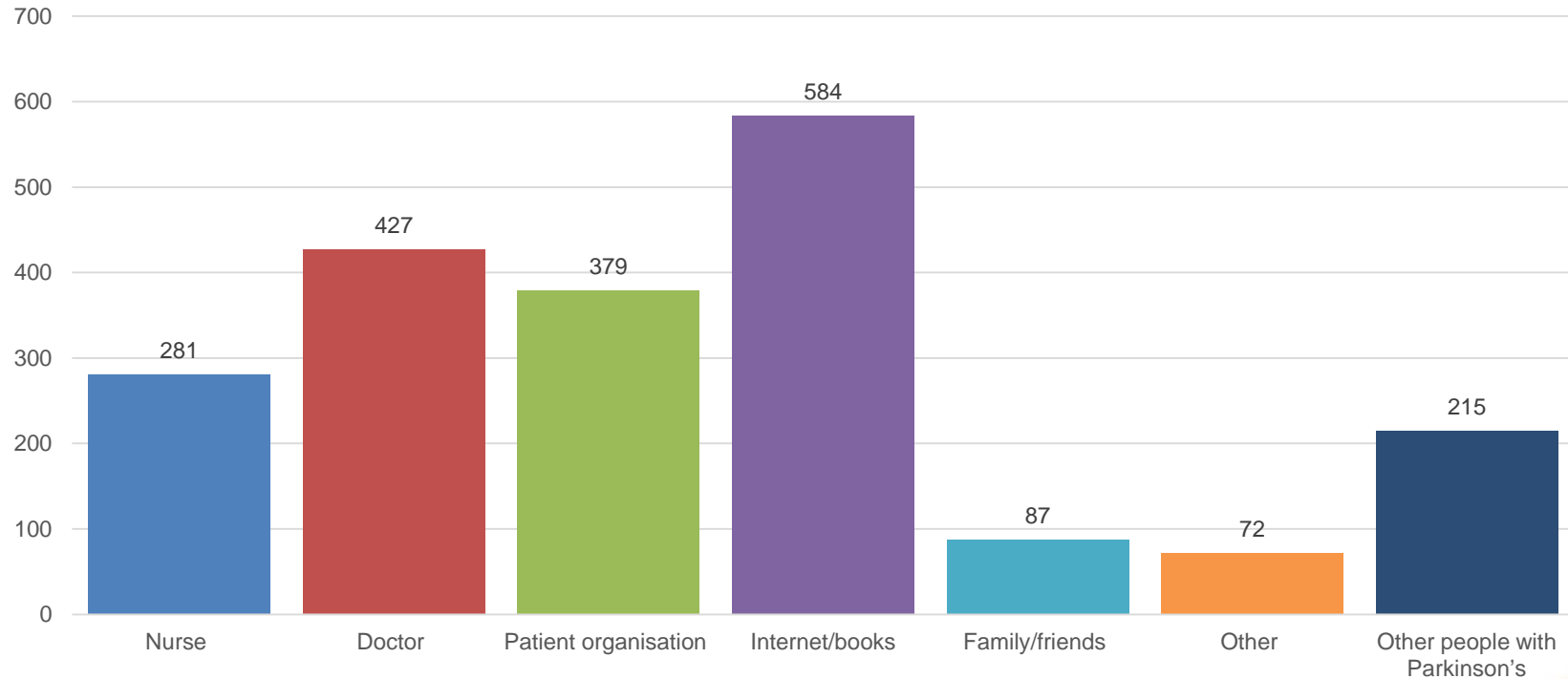


Do you actively seek information about Parkinson's?

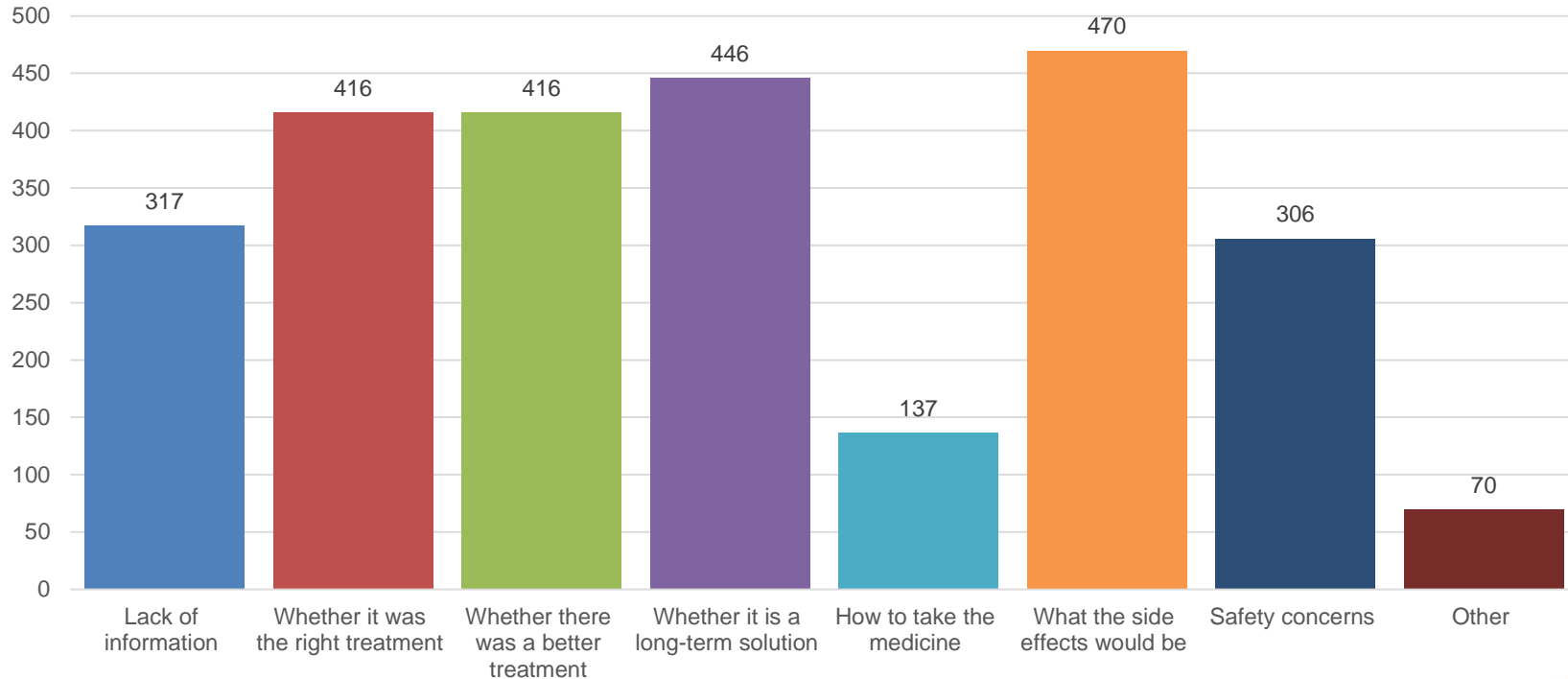


*842 participants completed this question from the 984 full responders

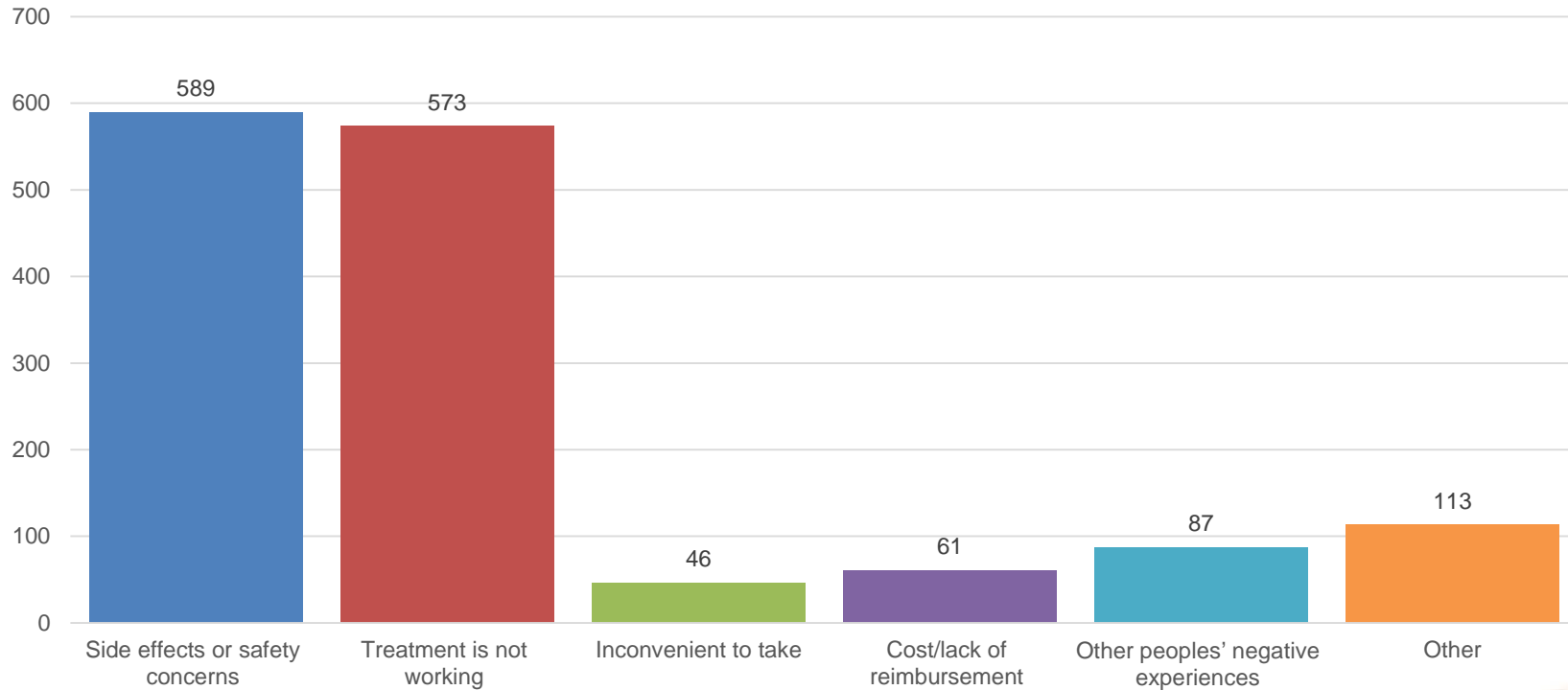
If yes, what are the most reliable sources of information?



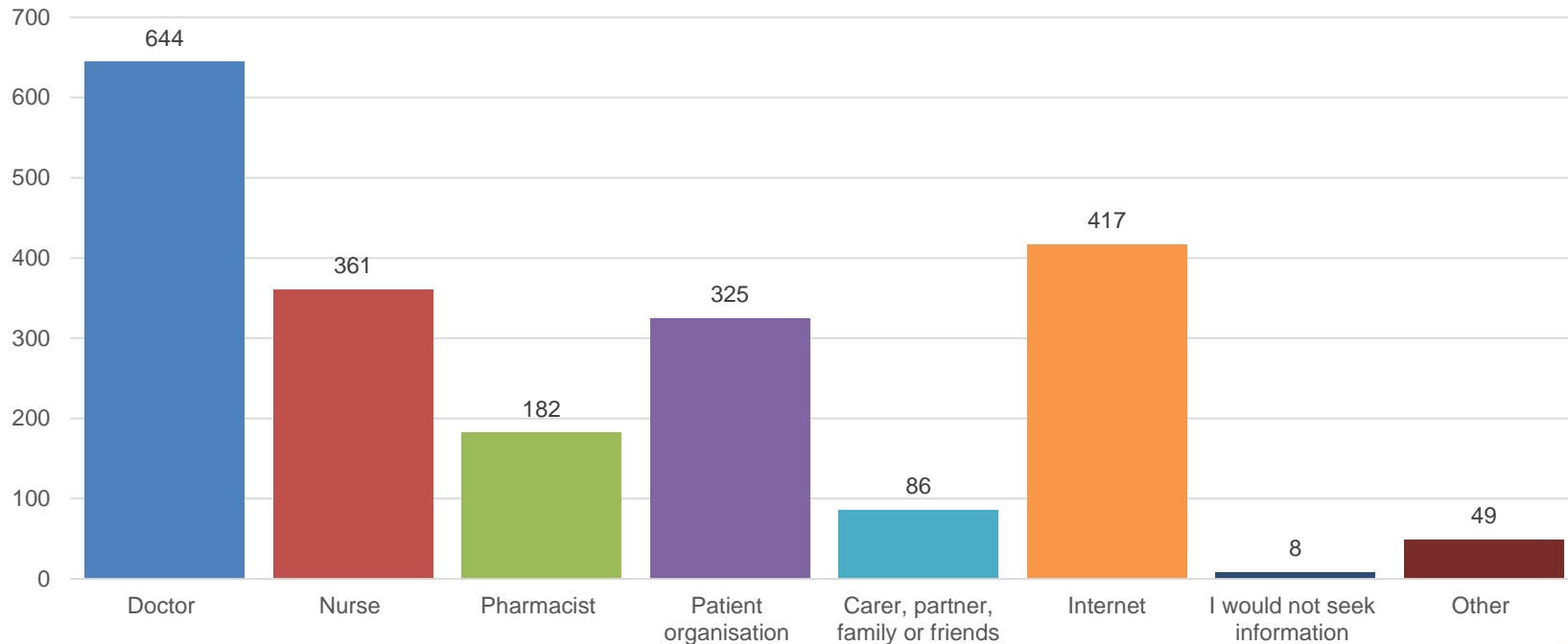
What were your major concerns when the Parkinson's treatment began?



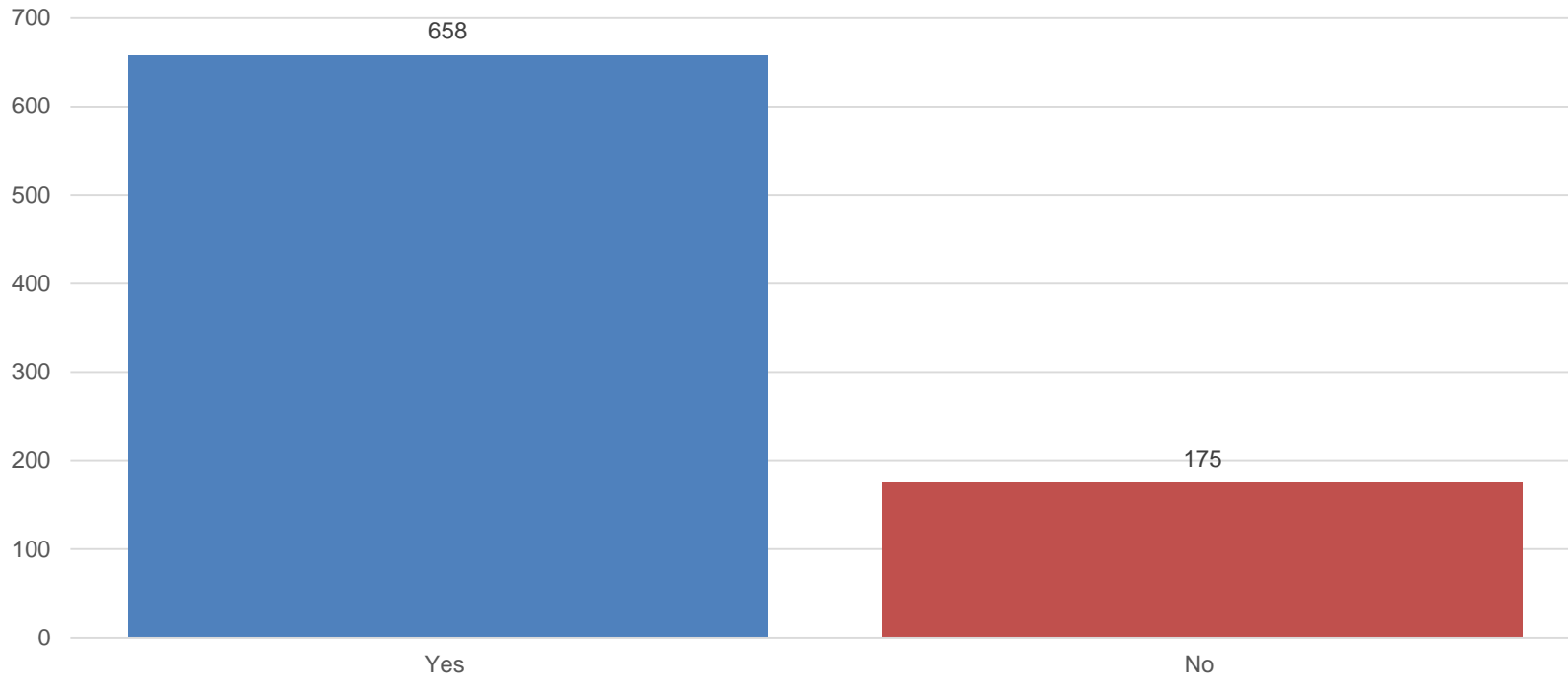
What would be the main reason for stopping a treatment?



If you had problems or questions about Parkinson's medication or treatment, where would you go to seek information to help you?

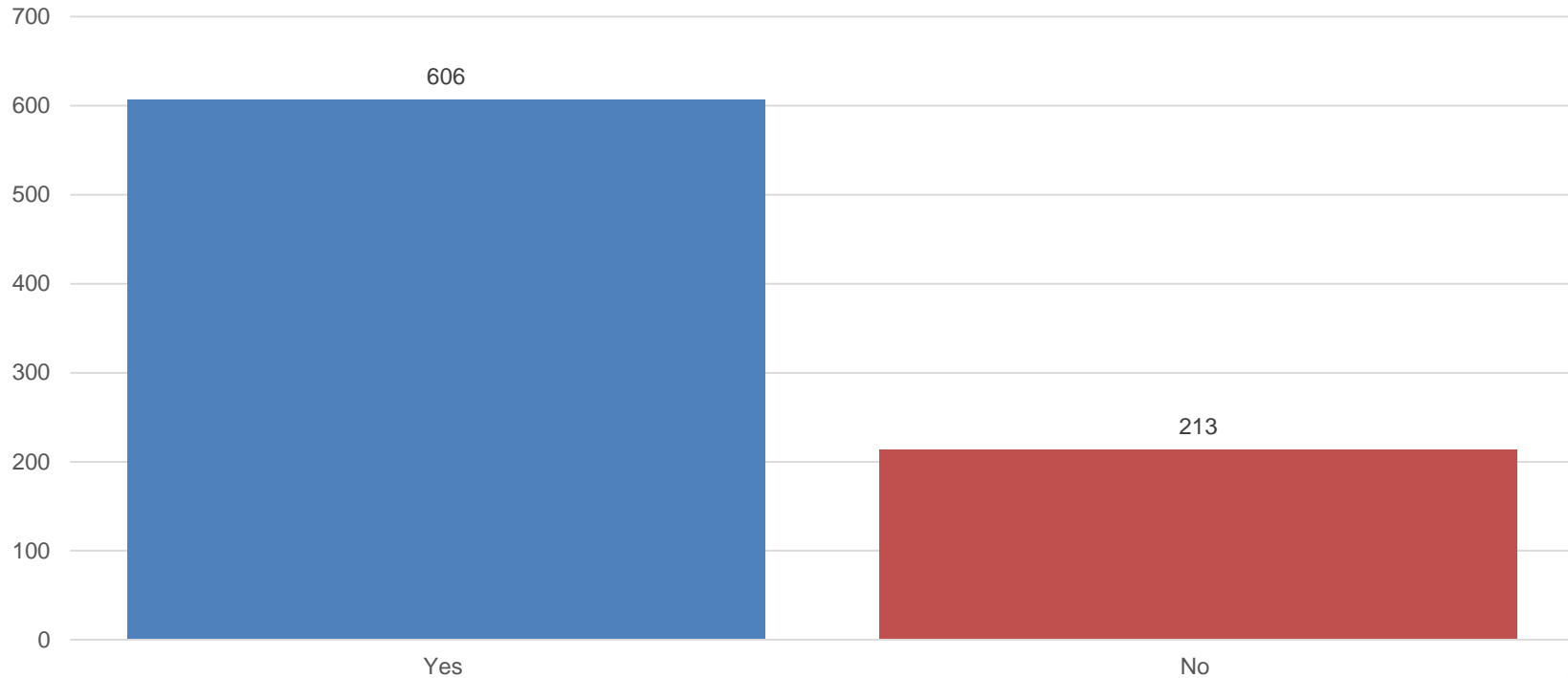


*Do you feel that you have lost your independence – or will lose it over time?



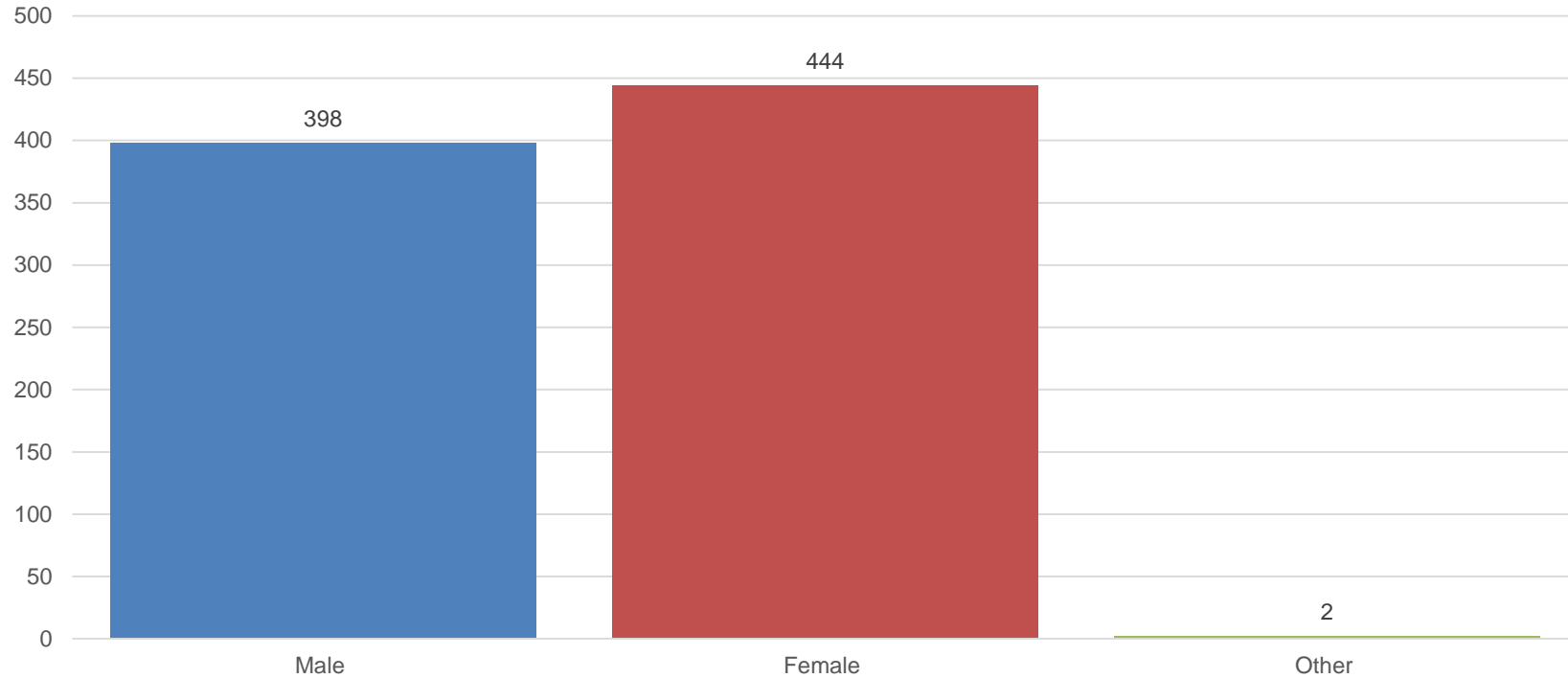
*833 participants completed this question from the 984 full responders

*Have you discussed your concerns with your partner, carer, family and friends?



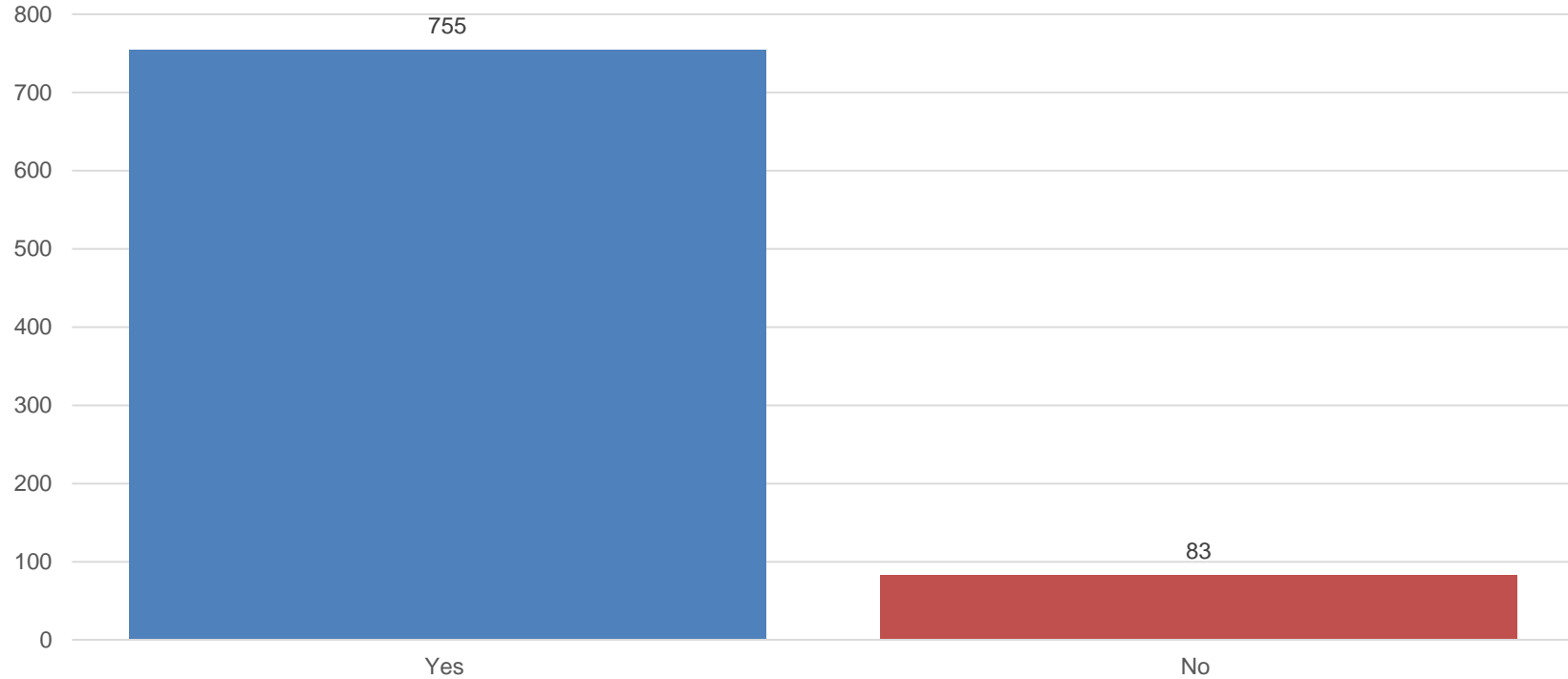
*819 participants completed this question from the 984 full responders

*Gender of survey respondents



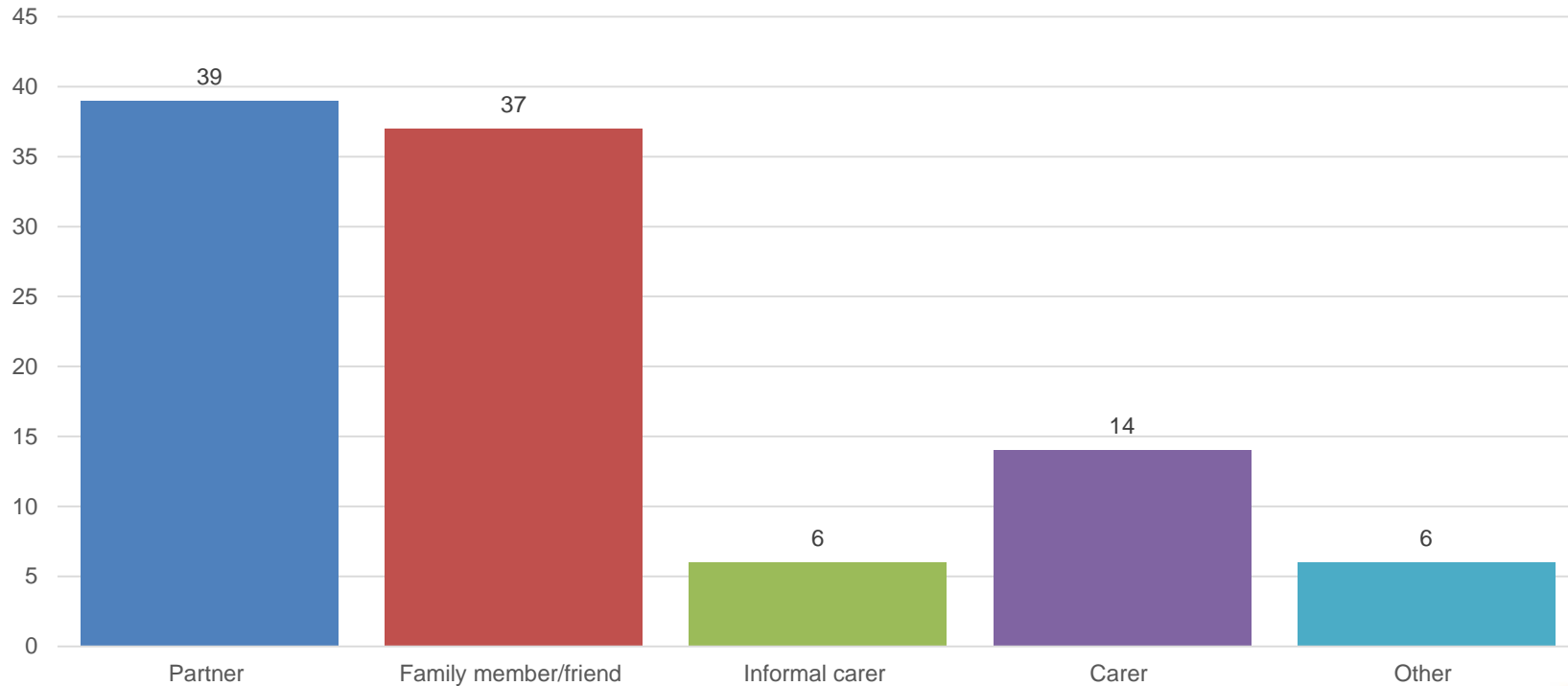
*844 participants completed this question from the 984 full responders

*Do you have Parkinson's?



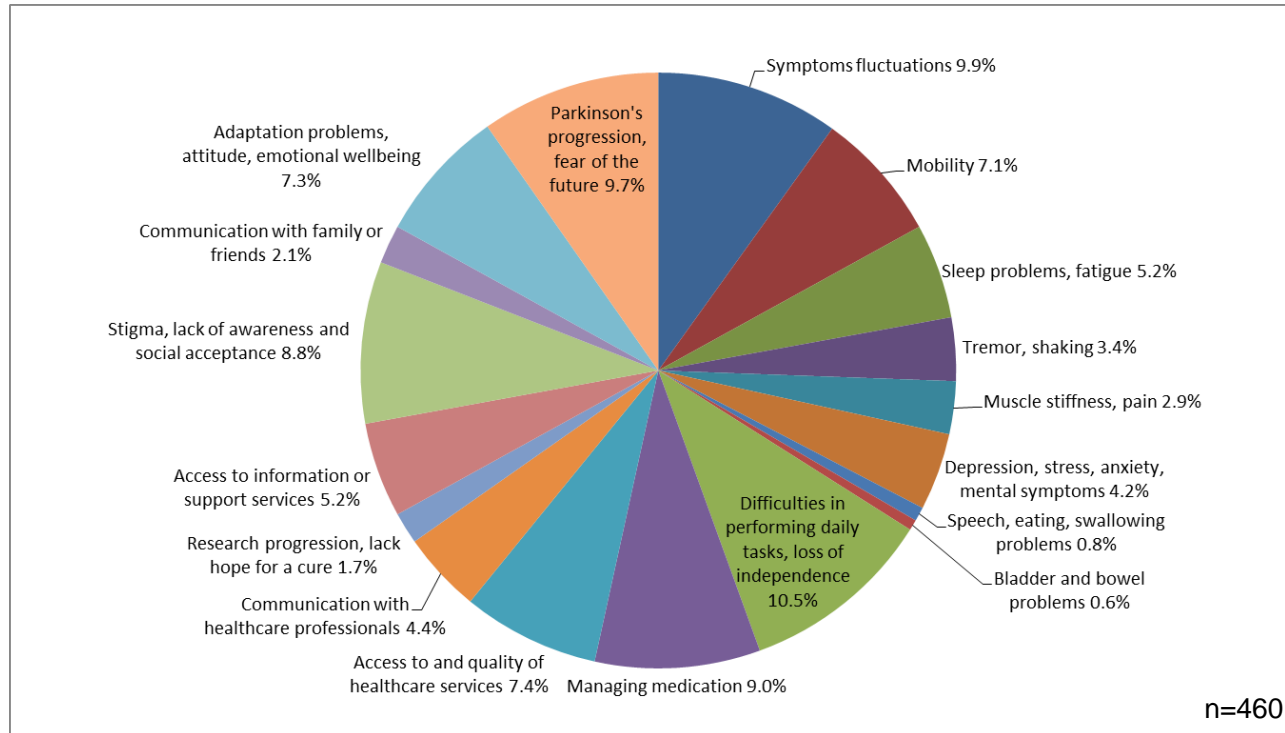
*838 participants completed this question from the 984 full responders

*If no, what is your relationship to the person with Parkinson's?



Analysis of free text responses, aggregate data for Europe (p32-40)

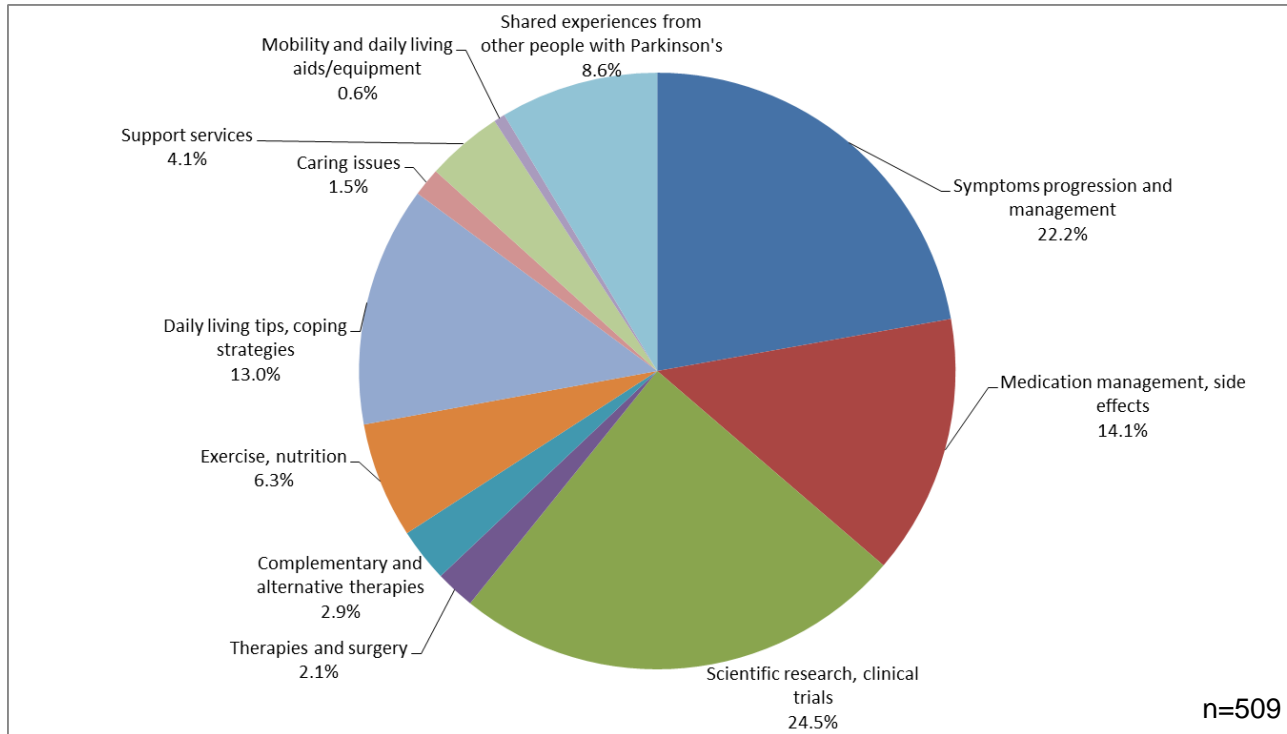
*What do you feel is the biggest hurdle when managing Parkinson's?



*460 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

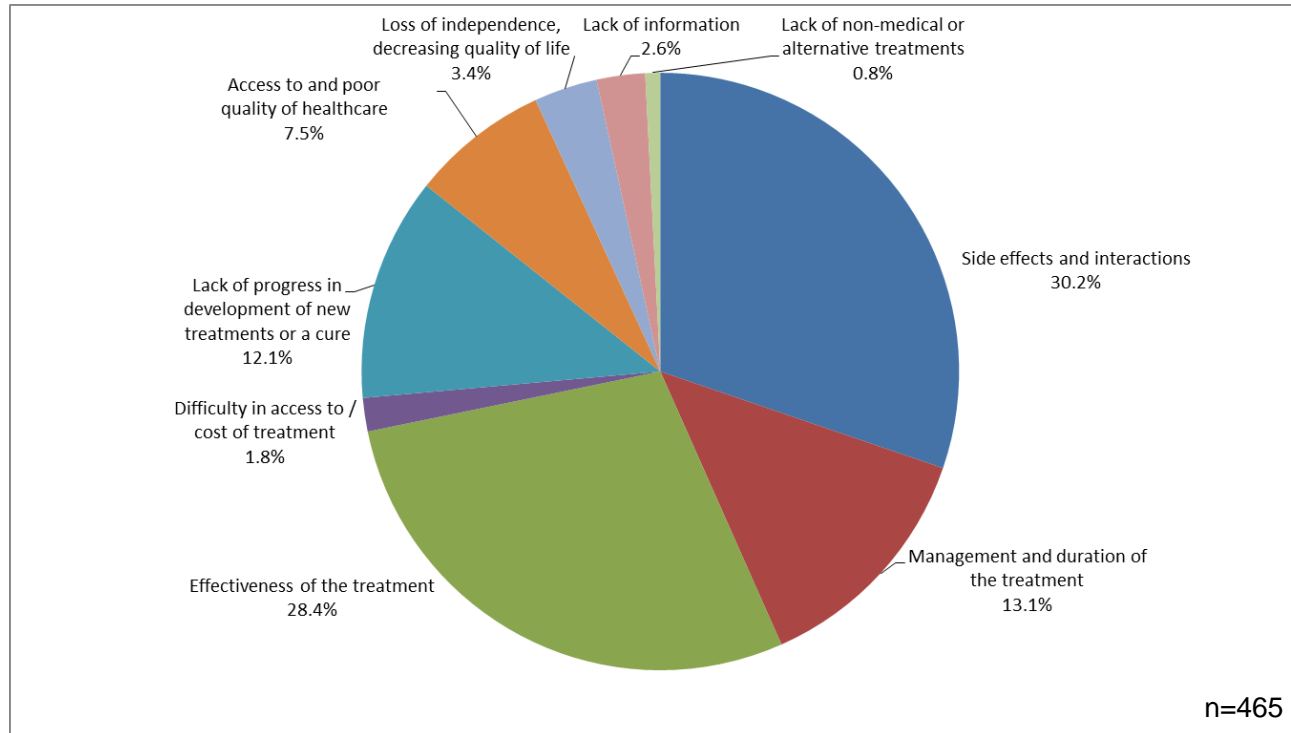
*What type of information do you seek?



*509 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

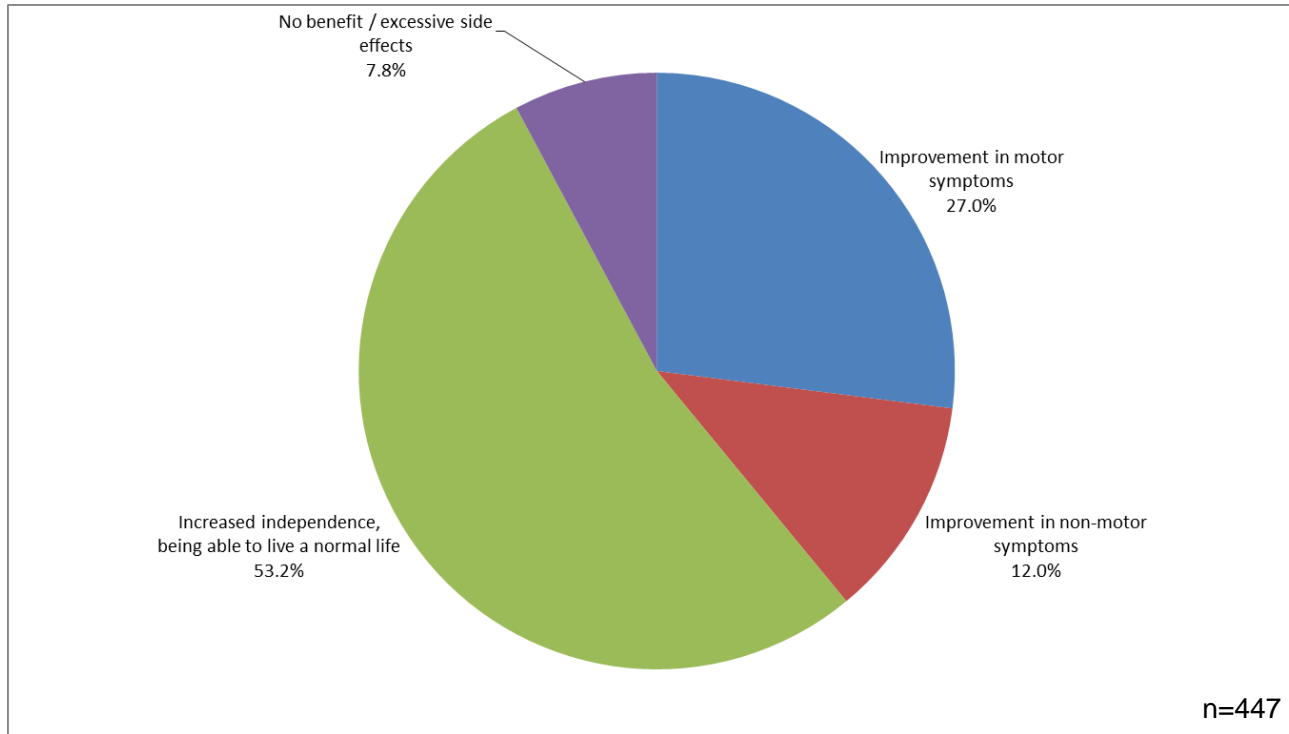
*What troubles you the most about the Parkinson's treatment?



*465 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

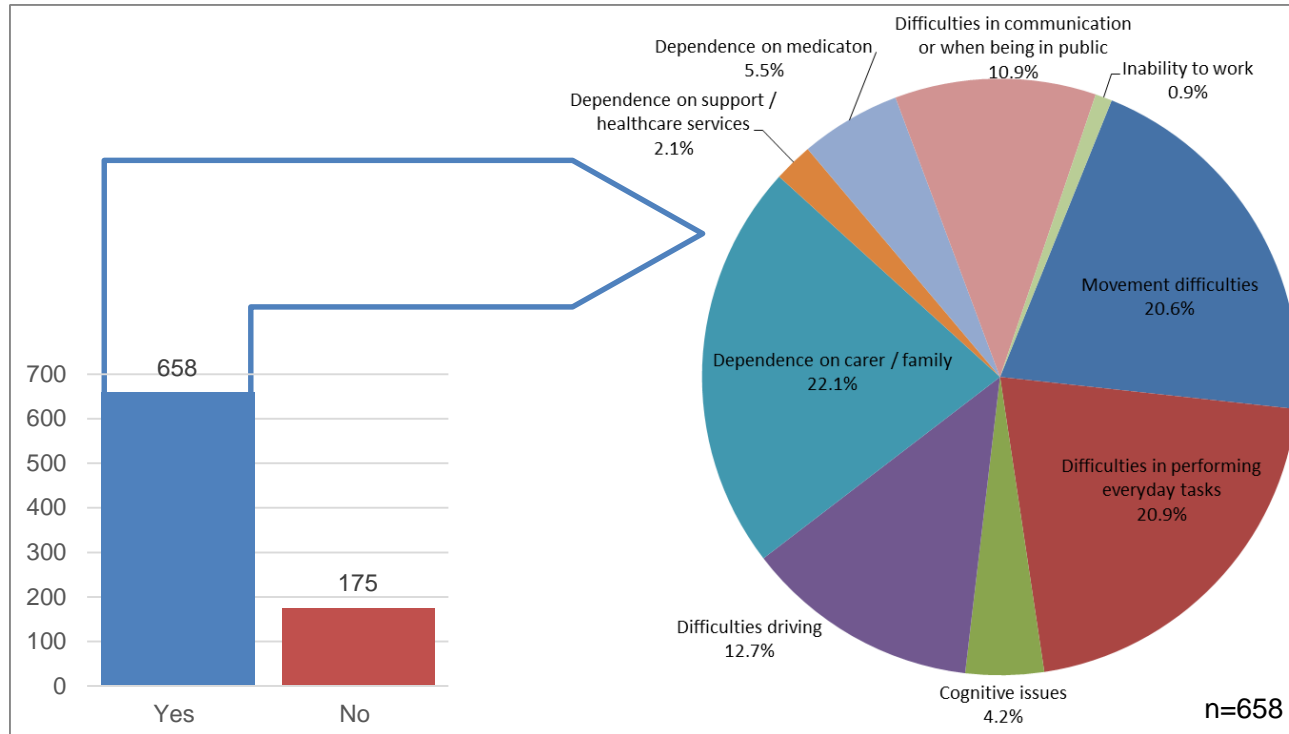
*What is the benefit to you when a treatment works?



*447 participants completed this question from the 984 full responders

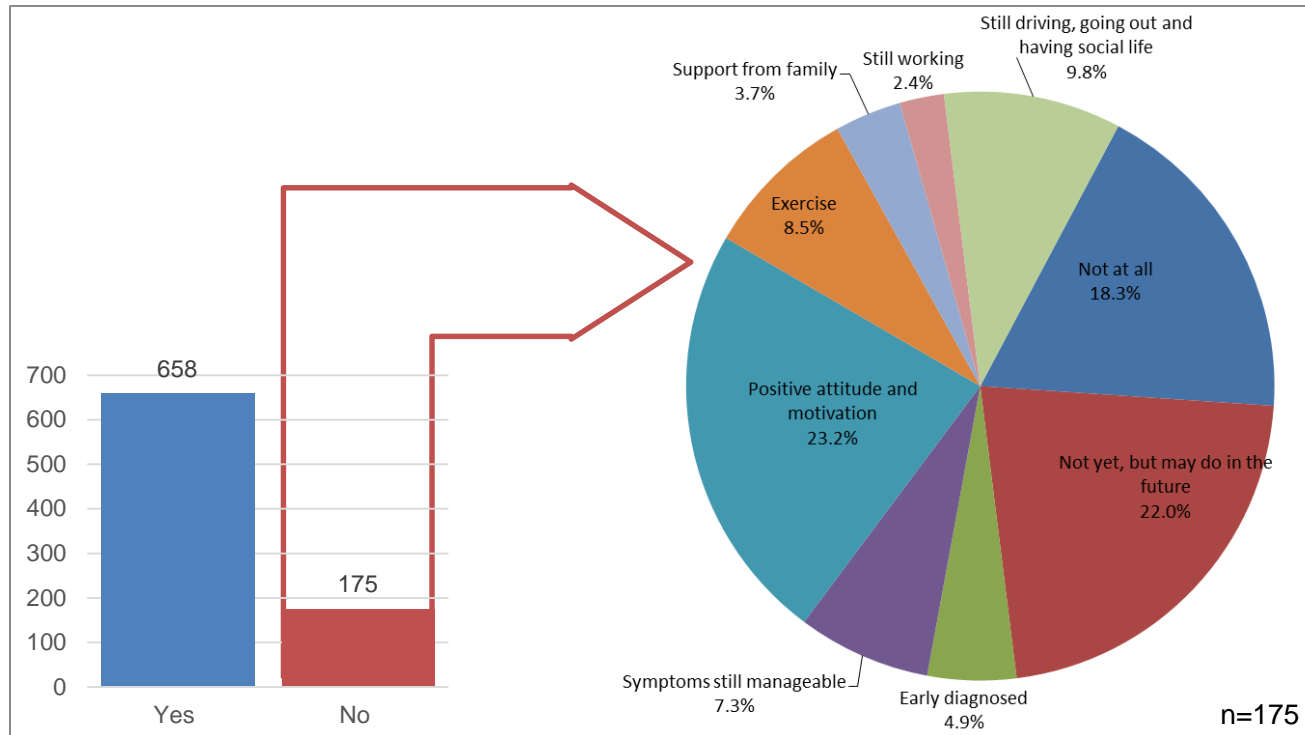
All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

*Do you feel that you have lost your independence – or will lose it over time? Why? (I)



*833 participants completed this question from the 984 full responders
 All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

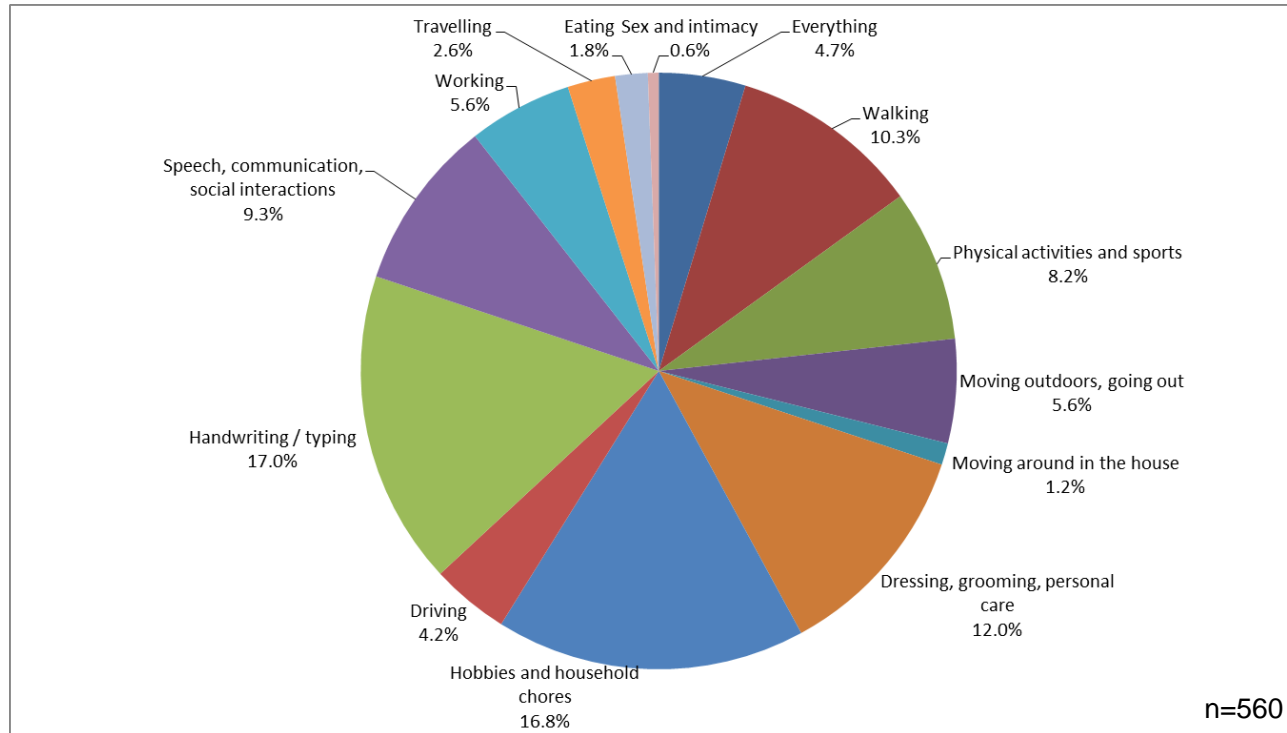
*Do you feel that you have lost your independence – or will lose it over time? Why? (II)



*833 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

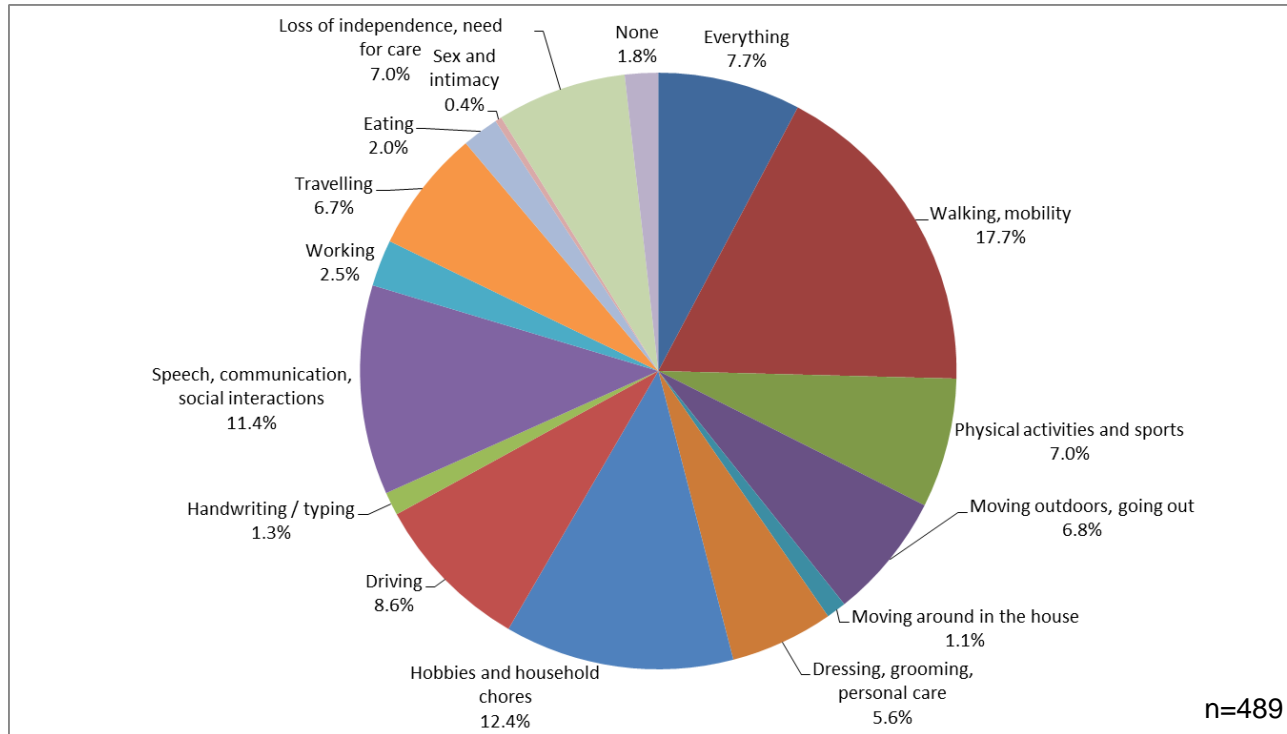
*Which of your daily life activities have changed because of Parkinson's?



*560 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

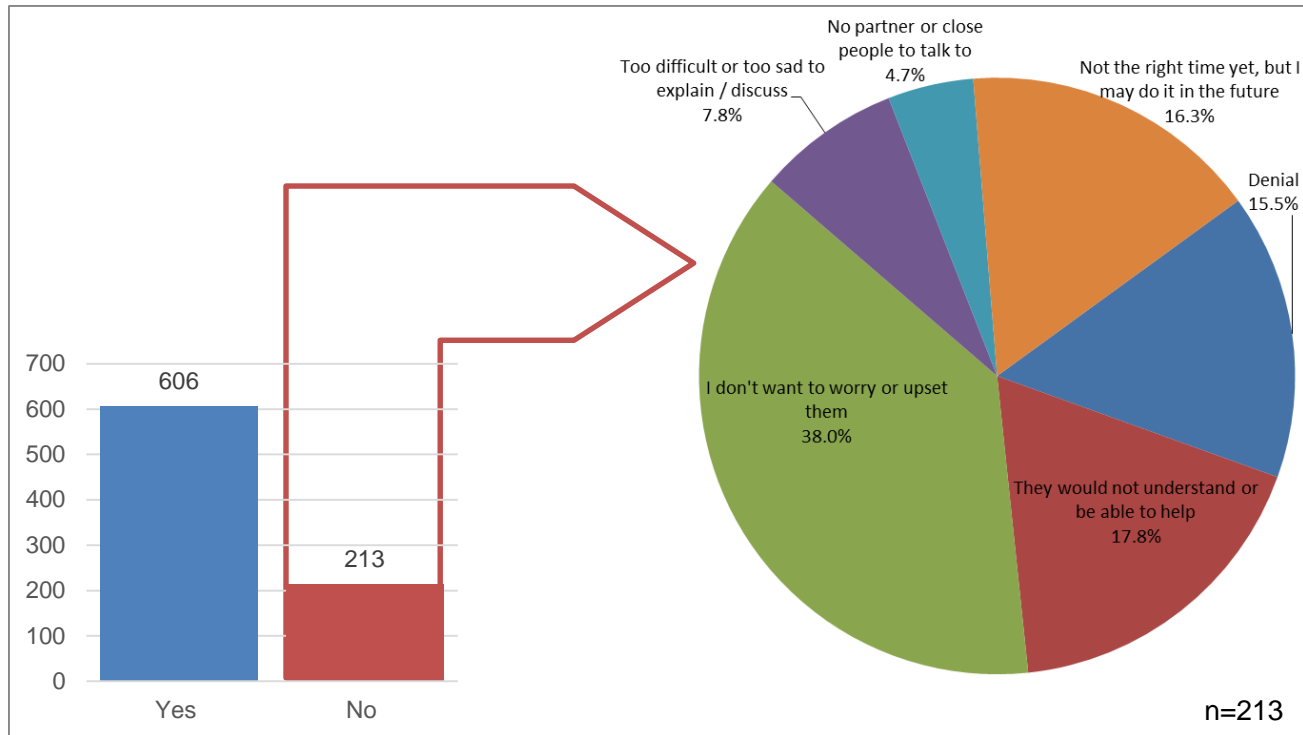
*What future activities do you feel will change as a result of Parkinson's?



*489 participants completed this question from the 984 full responders

All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.

*Have you discussed your concerns with your partner, carer, family and friends? If no, why?



*819 participants completed this question from the 984 full responders
 All relevant adverse events that were captured have been reported in line with adverse event reporting requirements.