

# Real Life, Real PD Survey

Final Pan-European Survey Results

# Survey Objectives

**The survey was carried out to provide insights into the realities of living with PD and to highlight some of the symptoms of PD that are less widely discussed**

By looking at:

- 'Real life' everyday concerns faced by people with PD
- Fundamental areas of daily living such as eating, dressing and emotional well being
- Effects of mood on relationships with family members and friends
- Problems associated with disturbances in sleeping through the night or waking up tired
- To illustrate 24-hours in the life of a person with PD

The Real Life, Real PD survey was supported by GlaxoSmithKline

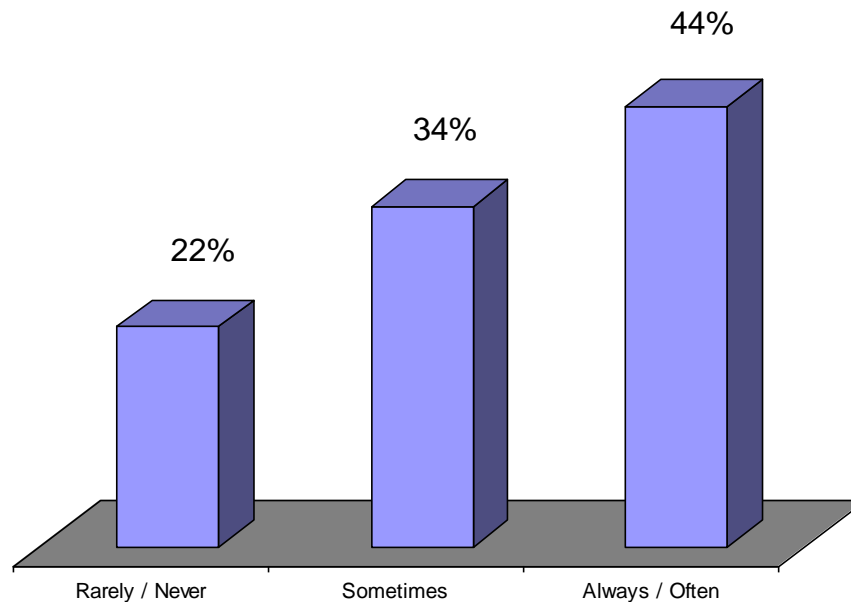
# Survey Background

- Launched online via the European Parkinson's Disease Association (EPDA) website across 31 European countries in October 2007
- Participating countries were Andorra, Armenia, Austria, Azerbaijan, Belgium, Bosnia, Bulgaria, Czech Republic, Denmark, Estonia, Faeroe Islands, Finland, France, Georgia, Germany, Ireland, Italy, Lithuania, Luxembourg, Netherlands, Norway, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine and the UK
- Questionnaire developed in partnership with a pan-European steering committee of PD experts
- Recruitment of people via local EPDA member organisations
- Interim data analysis at the end of November 2007, final data analysis at the end of February 2008, via an independent research company
- Local results disseminated to EPDA member organisations at the end of March 2008

# Key Findings

# Symptom Control

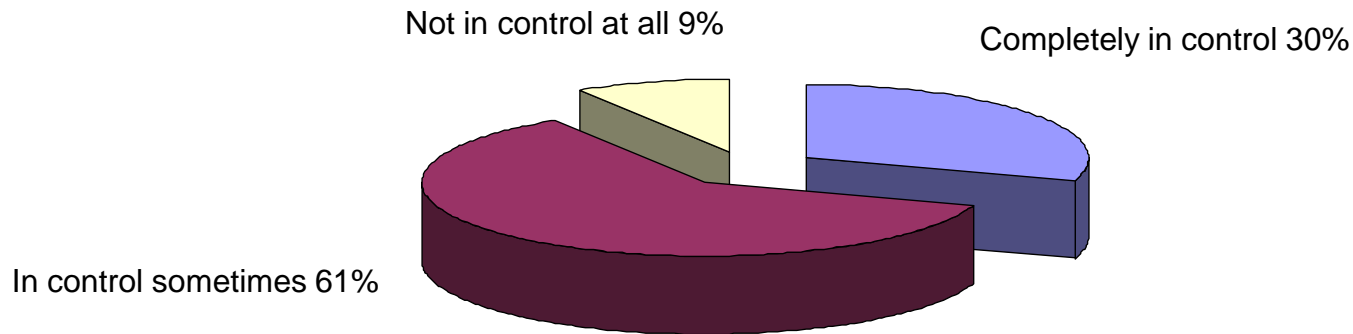
- **Over two thirds** of respondents did not feel in control of their symptoms over a 24 hour period
- **Three out of four** said that their PD affects their ability to function throughout the day



**Q. Does your PD affect your ability to function properly in the morning and throughout the day?**

# Medication

- **Over half** need to plan their day around the times they take their medication



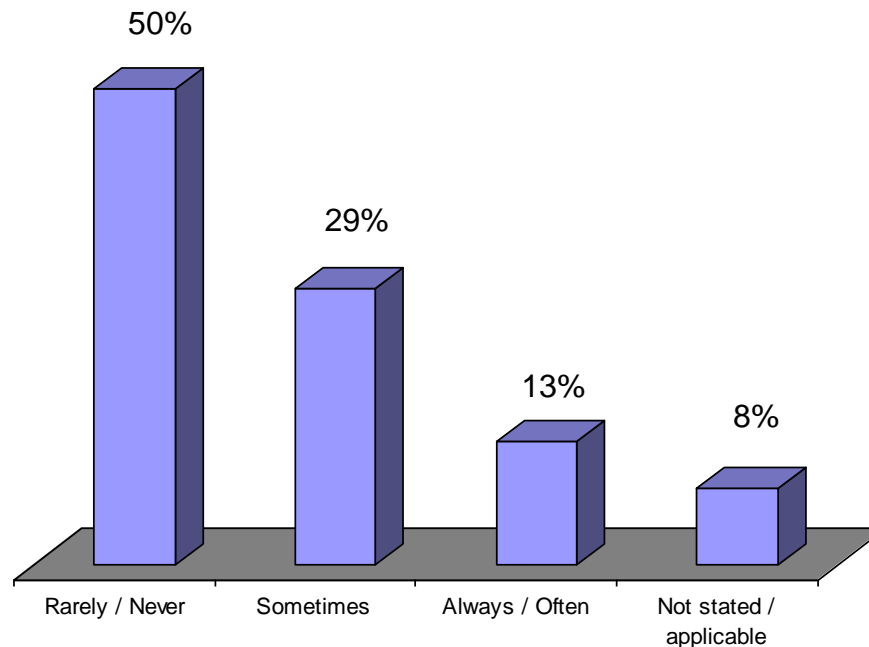
**Q. Do you feel in control of your symptoms over a 24 hour period?**

# Daily Life

- **60%** of respondents reported difficulties in maintaining balance
- **Over half** have problems washing, bathing and dressing
- **Over half** suffer memory loss as a result of their PD
- **Nearly half** reported problems with self-organisation and speaking
- **42%** experience difficulties driving
- **Over a third** reported difficulties with eating and drinking

# Sense of Wellbeing

- **42%** of people with PD stated that their moods can negatively affect their relationships
  - **Anxiety, frustration** and **worry** are the three most prevalent emotional symptoms experienced



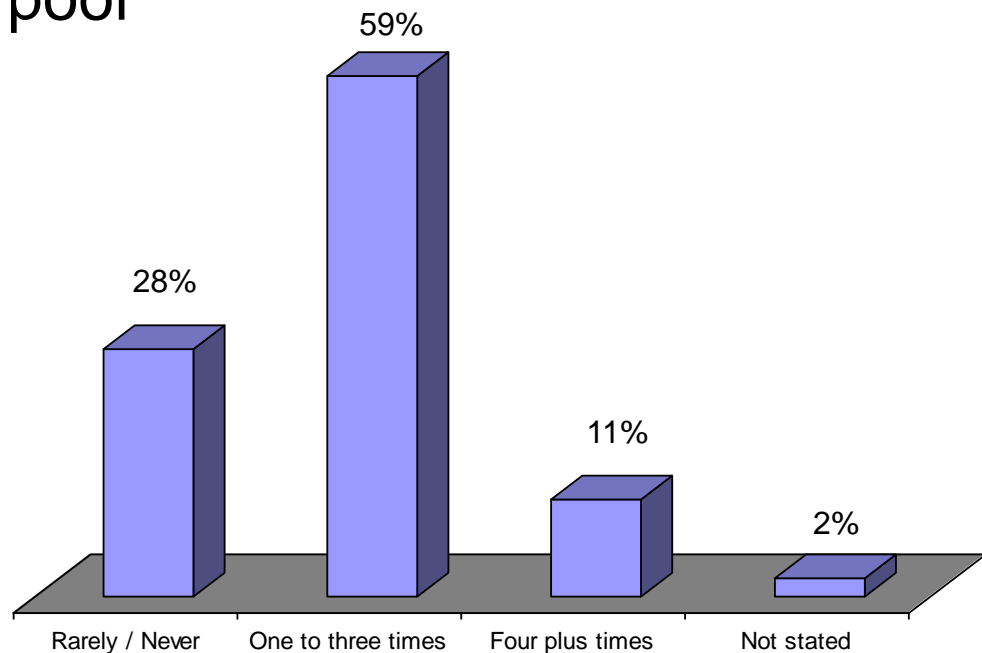
**Q: Do your moods negatively affect your relationships with friends, colleagues and family members?**



# Sleep Patterns

- **Nearly three quarters** of respondents experience difficulties in getting to sleep as a result of their PD
  - **70%** wake at least once during the night as a result of their PD
- **Nearly a quarter** of respondents rate the quality of their sleep as poor / very poor

**Q. How often do you wake during the night as a result of your PD?**



# What do People With PD Want?

## Q. Which areas would you like to improve most about your condition?

- Daily living activities
- Feeling less tired
- Achieving a sense of wellbeing
- Sleeping through the night
- Being tied to a medication regime
- Relationships with family / friends
- Experiencing negative moods

Most important



Least important

# Conclusions

- The survey demonstrates that PD patients frequently experience problems in symptom control over a 24 hour period
- Strict medication regimes mean that patients often need to plan their day around the times they take their medication
- The unpredictability of PD affects patients' ability to function throughout the day and can cause difficulties in performing everyday activities
- PD can also result in sleep problems and can have a negative impact on emotional wellbeing