



Survey Executive Summary

Perceptions of
Parkinson's Disease

Summary of Market Research carried out by ICM Healthcare, April 2009

Foreword

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Parkinson's disease is the second most common degenerative disorder of the central nervous system that often impairs the patient's motor skills and speech. In 2007 there were approximately 1.45 million people with Parkinson's across US, Japan, France, Germany, Italy, Spain and the UK.

Parkinson's belongs to a group of conditions called movement disorders. It is characterised by muscle rigidity, tremor, a slowing of physical movement (bradykinesia) and, in extreme cases, a loss of physical movement (akinesia). As a consequence, people with Parkinson's have increasing difficulty with controlling their body movements.

Parkinson's is both a chronic and progressive illness, which results in a marked decrease in the health-related quality of life of people with Parkinson's and their carers and places a tremendous economic burden on society.

Overall cost estimates for Parkinson's vary from country to country, but the largest component of direct costs is typically nursing home care, while prescription medications are the smallest contributor. Indirect costs arising from lost productivity and carer burden tend to be high. For example the total cost in the UK has been estimated to be up to £3.3 billion annually.

As this is a life-changing condition with a huge cost burden, it is important that the general public are aware of Parkinson's and the symptoms associated with it. A recent clinical trial (ADAGIO) showed that people who received early treatment with one particular Parkinson's medicine showed slower progression of their disease¹. This only emphasises the importance of being able to recognise the symptoms of Parkinson's at an early stage.

As an initiative to explore the level of awareness around Parkinson's, Teva Pharmaceutical Industries Ltd and H. Lundbeck A/S in partnership with the European Parkinson's Disease Association (EPDA) conducted a survey of over 5,000 members of the general public from across Europe. The survey assessed general knowledge of the disease and its symptoms.

The results of the survey paint a shocking picture of the lack of Parkinson's awareness. Although there was some variation between countries – and surprisingly between men and women too – the survey reveals a general lack of understanding of this disease. The results of the survey highlight a need to raise awareness of the social and economic impact of Parkinson's in Europe to ensure that people receive the best care and treatment available.

Although almost 4 in 10 people know someone with Parkinson's, two thirds of the population don't understand the severity of the disease.

This Executive Summary highlights the main findings of the survey demonstrating this lack of understanding around the second most common degenerative disorder, Parkinson's.

Details of the Survey

"As well as the tremors of my hands and feet I also lost my sense of smell and that was the worst part for me as I love cooking."

Carl-Henrik, Sweden, diagnosed in 2004.

What is Parkinson's disease?

Parkinson's is a progressive, degenerative condition of the central nervous system (CNS), caused by the degeneration of dopaminergic neurons in the substantia nigra of the midbrain.

Methodology

- A total of 5010 on-line surveys conducted with respondents from the UK, France, Germany, Italy and Spain
- Approximately 1000 interviews per country
- Survey conducted in April 2009

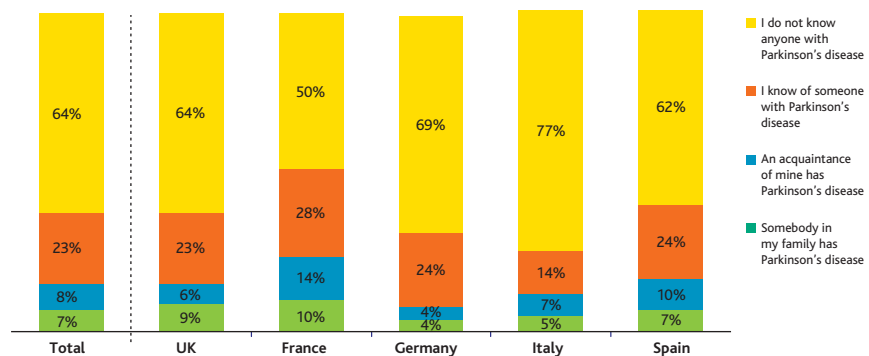
Key Findings

- Although 4 in 10 people know someone with Parkinson's, two thirds of the population do not know how widespread it is
- Only 44% of the population can identify Parkinson's as a neurological condition that affects a person's movement
- Shaking was the only symptom of Parkinson's that was widely recognised and 77% didn't recognise inability to move as a symptom
- Depression, a prominent feature of Parkinson's, occurs in 40-50% of people with Parkinson's, and 62% of people associate depression with Parkinson's yet only 6% of people see this as a main concern
- 91% of the general public do not think that they would feel isolated with Parkinson's, despite the proven physical and psychological effects it has on relationships, independence and confidence
- Men think that Parkinson's is 10 times less common than it actually is
- Women are more concerned about their future with respect to Parkinson's
- Women can better identify Parkinson's symptoms than men

4 in 10 people surveyed know someone with Parkinson's

Do you, or does someone in your family or someone that you know have Parkinson's disease?

Base: All respondents (n=5010)



Key Trends 1:

Gap in knowledge surrounding Parkinsons

Key Finding

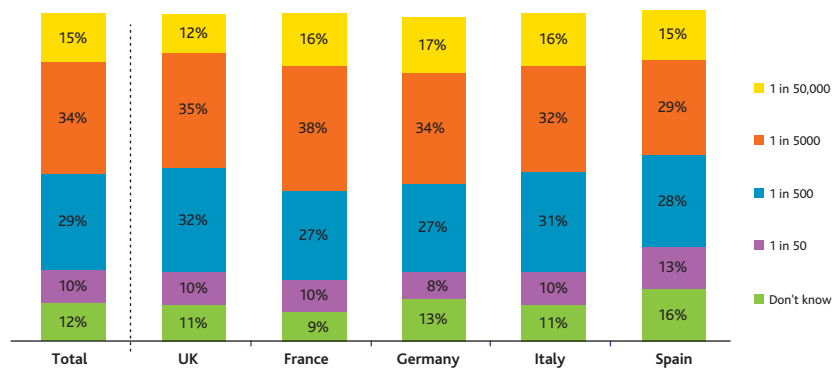
Although 4 in 10 people know someone with Parkinson's, two thirds of the population do not know how widespread it is (1 in 500 people are at risk)

How common is Parkinson's?

Average prevalence rates for Parkinson's have been estimated at between 740 and 920 per 100,000 people worldwide. Community based studies show the incidence rate (the number of new cases occurring in a specific time frame) is around 10 new cases per 100,000 people at age 50, rising to at least 200 per 100,000 people at age 80.

How common do you think Parkinson's disease is amongst the general population?

Base: All respondents (n=5010)

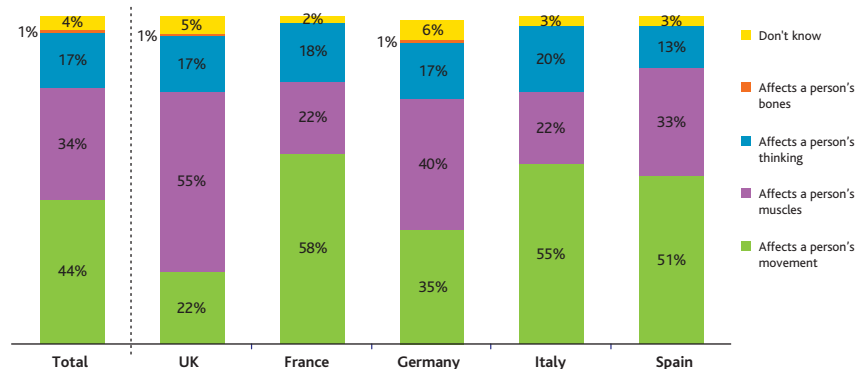


Key Finding

Only 44% of the population can identify Parkinson's as a neurological condition that affects a person's movement

Which of the following, if any, best describes the type of disease that Parkinson's disease is?

Base: All respondents (n=5010)



Key Finding

Shaking was the only symptom that was widely recognised and 77% didn't recognise inability to move as a symptom

Which, if any, of the following symptoms could be caused by Parkinson's disease?

Base: All respondents (n+5010)

	Total	Uk	France	Germany	Italy	Spain
Shaking	81%	86%	92%	67%	84%	76%
Muscle spasms	53%	71%	60%	42%	45%	47%
Lack of ability to remain still	46%	61%	47%	30%	49%	44%
Lack of balance	44%	64%	57%	40%	31%	26%
Inability to move	23%	29%	20%	42%	12%	12%
Pain	22%	36%	32%	23%	8%	9%
Seizures	12%	21%	6%	23%	5%	6%
Sickness	2%	6%	2%	1%	1%	1%
Dont'know	6%	6%	3%	12%	5%	3%

Key Finding

91% of the general public do not think that they would feel isolated with Parkinson's, despite the proven physical and psychological effects it has on relationships, independence and confidence

What would you worry you most about developing Parkinson's disease?

Base: All respondents (n+5010)

	Total	Uk	France	Germany	Italy	Spain
Living with tremor/shaking	31%	26%	34%	27%	33%	32%
Fear about the future	26%	39%	25%	20%	21%	26%
Isolation	9%	6%	11%	12%	8%	8%
Depression	6%	5%	7%	6%	7%	7%
Disorientation	5%	5%	4%	6%	4%	5%
Inability to sustain relationships	5%	4%	5%	5%	9%	4%
Loss of balance	4%	2%	5%	2%	5%	5%
Anxiety	3%	1%	1%	7%	1%	2%
Low self esteem	2%	2%	3%	1%	2%	3%
Dont'know	10%	10%	6%	12%	11%	9%

Key Trends 2:

There are important differences in understanding and beliefs about parkinsons between men and women

Key Finding

Women can better identify Parkinson's symptoms than men

Which, if any, of the following symptoms could be caused by Parkinson's disease?
Base: All respondents (n+5010)

	Male	Female	18-24 yrs old	25-34 yrs old	35-44 yrs old	45-54 yrs old	55-65 yrs old
Shaking	79%	83%	79%	79%	81%	83%	83%
Muscle spasms	49%	56%	56%	55%	52%	51%	50%
Lack of ability to remain still	45%	48%	48%	45%	46%	47%	47%
Lack of balance	41%	46%	43%	44%	43%	43%	47%
Inability to move	23%	24%	28%	23%	23%	22%	19%
Pain	18%	25%	27%	24%	20%	18%	21%
Seizures	12%	12%	17%	14%	11%	10%	10%
Sickness	2%	2%	3%	2%	3%	2%	1%
Dont'know	6%	6%	6%	7%	5%	5%	5%

Are men or women more likely to get Parkinson's?

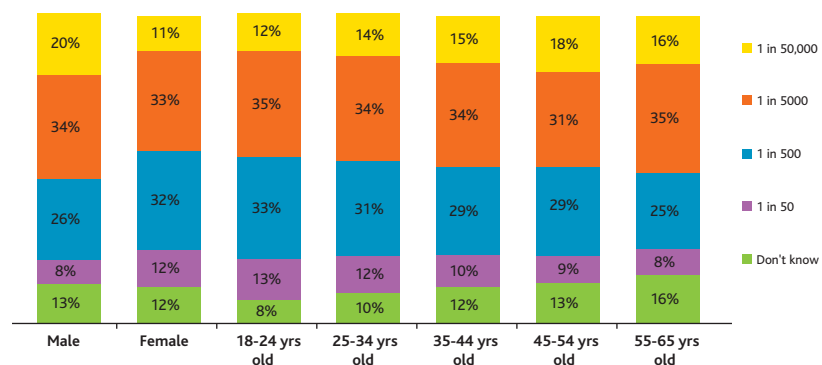
According to epidemiological studies carried out in Western countries, there are marginally more men with Parkinson's than women, although the reasons for this are unclear. Interestingly, the survey showed it was the women who tended to have a better understanding of the disease.

Key Finding

Men think that Parkinson's is 10 times less common than it actually is

How common do you think Parkinson's disease is amongst the general population?

Base: All respondents (n=5010)



Key Trends 3:

There were some key differences between european countries in how people view parkinsons

Key Finding

The majority of people in France believe that Parkinson's is not a life threatening disease, however only 34% of Germans and 27% of Italians believe this to be the case

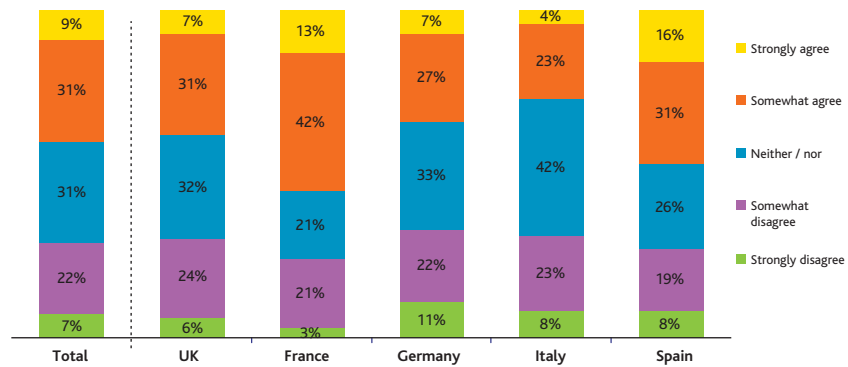
What is the average life expectancy?

The average life expectancy of people with Parkinson's is 88 at onset of Parkinson's at 65 years compared to 91 years in the general population

To what extent do you agree or disagree with the following statements?

– Parkinson's disease is not a life threatening condition and people can live with the condition for long periods of a relatively normal lifespan

Base: All respondents (n=5010)



Key Finding

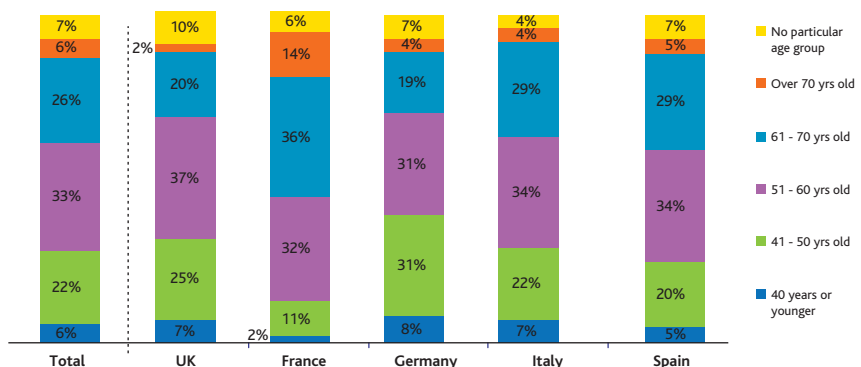
In France over half think that Parkinson's is most likely to be first diagnosed among those over sixty, whereas in the UK, for example, 69% think it is diagnosed under the age of 60

At what age do people get Parkinson's?

The mean age of onset of Parkinson's is approximately 60 years. It usually occurs in people over 50 years of age but can occasionally present in younger adults in their 30s to 50s (and rarely, even younger).

What do you think is the most likely age that people are FIRST diagnosed with Parkinson's disease?

Base: All respondents (n=5010)



Call to Action

“At first I could disguise the symptoms, sit on my shaking hand, fold my arms, but as time marched on, sitting on my hand just made the chair shake ... just walking from A to B became increasingly difficult, then impossible. As my walk got worse, I would sometimes dream that I had found my stride, and wake up, with tears streaming down my face.”

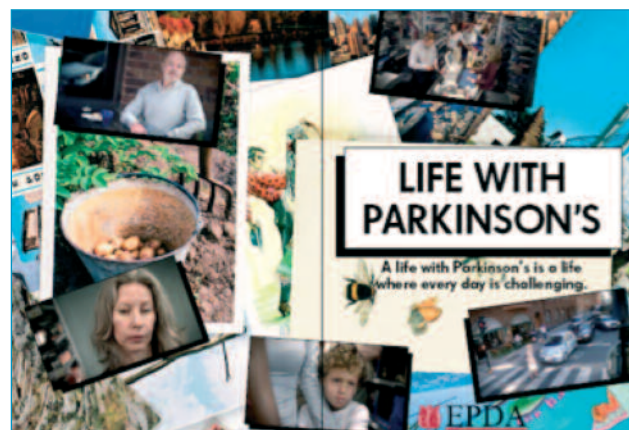
Ann, Ireland, 53,
diagnosed in 1996.

The outcome of the survey has highlighted:

There are major gaps in the general public's knowledge of Parkinson's disease

Action that is being taken:

The general public need to be alerted to the range of symptoms, the age of onset and how common the disease is. The EPDA recognises these needs and have launched an awareness campaign in order to raise awareness to the public on Parkinson's. This includes a booklet called *Life with Parkinson's* which focuses on the challenges of living with Parkinson's. With support from an educational grant from Teva Pharmaceutical Industries Ltd and H. Lundbeck A/S the *Life with Parkinson's* booklet is being translated into 9 European languages.



Managing Parkinson's

Parkinson's is a progressive disease with no current cure available and symptoms gradually worsen as time goes on. So, as soon as early signs of Parkinson's are detected, medical advice should be sought. By slowing down the progression of the disease, people with Parkinson's can maintain a good quality of life for longer.