

Let's talk about Parkinson's

Setting the right policy agenda at the European level

What is Parkinson's disease? The facts and figures



A progressive, chronic and complex neurodegenerative disease

that has no

cure.

Affecting all aspects of daily living, the disease invariably impacts the physical, cognitive and psychological domains, across nearly every cultural, social and economic boundary.

60 years

Average age of onset, with 1 in 10 under 50

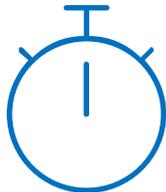
The disease is predominantly characterised by problems with body movements, known as **motor symptoms**, including tremor, rigidity, and instability. However, it is also associated with **non-motor symptoms**, including postural sleep disturbances, anxiety, depression, hallucinations, psychosis, dementia and many more.

postural
sleep

Parkinson's is a **highly individual disease** that differs from person to person, which requires a personalised approach to treatment and care.

People living with Parkinson's in Europe, forecast to double by 2030 (EBC, 2011)

1.2 million



A major public health and socio economic challenge

Treatments are available for a number of aspects of Parkinson's, but are not yet accessible for all.

There are significant impediments to individualised care, including inaccurate and delayed diagnosis of patients, and the fact that people who are correctly diagnosed will need medication for the rest of their lives.

Indeed even treatments can lose their effectiveness with time, and often cause unpleasant side effects. There is a clear lack of a holistic approach to treatment, both at the European level and across Member States.

The cost per patient amounts to approximately €11,000 every year on average across Europe, with the disease costing Europe **€13.9bn annually**¹.

The cost per person each year also increases 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.

¹ European Brain Council, *Costs of Disorders of the Brain in Europe* (2011)



What can the EU do?

Parkinson's represents a serious challenge to the EU's objective to achieve sustainable healthcare systems and promote healthy social and economic development across the continent. Despite this, **Parkinson's could be better addressed at the European level and in many Member States.**

The European Parkinson's Disease Association (EPDA) believes that much can be done to overcome key hurdles to effective diagnosis, treatment and care at the European level. In partnership and collaboration with the Member States and regional and local health authorities, we are urging the EU to take the following steps for people with Parkinson's disease:

1. Identify Parkinson's disease as a priority public health challenge

- Raise the challenges posed by Parkinson's in EU workstreams related to access to medicines, health and long-term care, as well as in the activities on integrated care conducted jointly by European Commission and Member States.
- Put Parkinson's disease on the agenda of forthcoming Presidencies of the European Union in 2017, to mark the bi-centenary anniversary of the discoveries of the disease and to encourage Member States to take targeted action to address Parkinson's at the country level.

2. Improve data collection systems on Parkinson's disease

- Include up-to-date information on Parkinson's in the forthcoming 'State of Health in Europe' cycle, which would help to demonstrate the impact of the disease on health systems.
- Consider developing a model for disease registries, based on existing good practices at national and regional level.
- Explore the possibility for the creation of European Reference Networks (ERN), with specific regards to rare forms and advanced stages of Parkinson's disease.

3. Provide financial support for added value projects

- Streamline funding for projects that improve the lives of people with Parkinson's and their families, such as the EPDA's landmark initiative, [My PD Journey](#), and the concluded European Cooperative Network for Research, Diagnosis and Therapy of Parkinson's (EuroPa).
- Provide funding through the Public Health Programme for training on Parkinson's disease for healthcare professional such as general practitioners, nursing homes and hospital staff.
- Facilitate scaling up of projects that aim to reduce waiting times for diagnosis and improve collaboration between primary and secondary care with the help of innovative technologies, such as the [Consultative Neurology](#) project in Sweden.

About the EPDA

A non-political, non-religious and not-for-profit organisation | The only European Parkinson's disease umbrella association

We [represent](#) national Parkinson's associations in nearly 30 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 is currently focusing much of its efforts on the My PD Journey project, which is a multi-stakeholder initiative for people with Parkinson's in Europe involving stakeholders from across the entire Parkinson's community. For more information on its flagship initiatives and activities, please see www.mypdjourney.com. For inquiries about the EPDA's political advocacy work and policy agenda, please contact secretariat@mpdj.eu.