

# Let's talk about Parkinson's

## What is Parkinson's disease? A major public health and socio-economic challenge

A **progressive, chronic and complex neurodegenerative disease that has no cure**. Affecting all aspects of daily living, the condition invariably impacts the physical, cognitive and psychological domains, across nearly every cultural, social and economic boundary.

Parkinson's is predominantly characterised by problems with body movements, known as **motor symptoms**, including tremor, rigidity, and postural instability. However, it is also associated with **non-motor symptoms**, including sleep disturbances, anxiety, depression, hallucinations and psychosis, and dementia. Parkinson's is also a **highly individual condition** that differs from person to person, which requires a personalised approach to treatment and care.

There are currently more than **1.2 million people** living with Parkinson's in Europe and this number is forecast to double by 2030. Worryingly the global prevalence of Parkinson's disease is increasing over time and it is expected to double within the next 20 years (up to 2% in people over the age of 60 and 6% in people over 80 years)<sup>1</sup>.

The cost per Parkinson's patient amounts to approximately €11,000 on average across Europe, and a cost to Europe of **€13.9bn annually**<sup>2</sup>. The cost per person each year also increases as the condition becomes more severe, while non-motor symptoms are a major source of hospitalisation and institutionalisation – both key cost-drivers in Parkinson's care.

## Key challenges and unmet needs in the management of Parkinson's<sup>3</sup>

In clinical settings, **Parkinson's is commonly missed or misdiagnosed since many of its symptoms are also common to other diseases**, both neurodegenerative and non-neurodegenerative. There is no diagnostically conclusive test for Parkinson's yet, so the diagnosis is clinical in nature. The diagnosis and treatment of Parkinson's typically occurs when the disease has already progressed to a relatively advanced stage in which motor symptoms are clearly evident and substantial neurophysiological damage has already taken place. At this point, any possibility of delaying disease progression or achieving neuroprotection may already be out of reach.

**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. Even treatments can lose their effectiveness with time, and often cause unpleasant side effects.

There are numerous advantages that may be associated with early therapeutic intervention in Parkinson's. Clinical trials also suggest that early treatment can slow disease progression. Both the decrease of symptoms and the potential for slowing disease progression have a major impact on improving quality of life and reducing the costs associated with Parkinson's disease in the long run, as the great majority of costs attributable to Parkinson's occur when the condition is at its most advanced stage.

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<sup>1</sup> Michela Tinelli, Panos Kanavos, Federico Grimaccia (LSE), *The value of early diagnosis in treatment in Parkinson's disease - A literature review of the potential clinical and socioeconomic impact of targeting unmet needs in Parkinson's disease* (2016)

<sup>2</sup> European Brain Council, *Costs of Disorders of the Brain in Europe* (2010)

<sup>3</sup> Michela Tinelli, Panos Kanavos, Federico Grimaccia (LSE), *The value of early diagnosis in treatment in Parkinson's disease - A literature review of the potential clinical and socioeconomic impact of targeting unmet needs in Parkinson's disease* (2016)

**Non-adherence is common, critical, and costly in Parkinson's.** It presents serious socio-economic consequences and well-being deterioration, not only for people with the condition, but also for family members. In general, people with PD have poor adherence to prescribed therapies, especially therapies with complex dosing schedules. The benefit of more convenient and adherence-friendly drug formulations, regimen simplification, reminders or reinforcement, counselling, and supportive care could further help to improve outcomes and lower costs.

**Targeting those unmet needs in the management of Parkinson's disease is crucial for addressing the growing socioeconomic burden of the disease and to ensure sustainability in the treatment of this chronic condition.**

### **What is needed to achieve timely diagnosis and optimal treatment in Europe?**

There is a clear lack of a holistic approach to treatment, both at the European level and across Member States. As indicated within the work of My PD Journey<sup>4</sup>, to provide optimal management of people with Parkinson's there remains a need to respond to the following recommendations:

1. People with Parkinson's should receive a **personalised approach to treatment and care** – one that is tailored to individual needs and preferences.
2. People with Parkinson's should have **access to - and be referred within six months to - appropriate healthcare professionals** with a specialty in Parkinson's. This should apply both to the diagnosis (by a neurologist or doctor with a special interest in Parkinson's) as well as the continued management and review of the disease (by a multidisciplinary team of experts).
3. People with Parkinson's and their carers should have access to a Parkinson's healthcare professional who is **trained to monitor and manage progression**, be a continuing point of contact for support (including home visits) when appropriate, and provide a reliable source of information about clinical and social issues.
4. It is essential that **coordination and communication between primary and secondary healthcare professionals** are significantly improved and that monitoring methods be developed. This will ensure that care plans remain consistent, regular and cohesive, resulting in people's individual needs and preferences being met.
5. **It is vital that we improve training about Parkinson's** for professionals working in nursing homes and general hospital wards.
6. People with Parkinson's and their carers should **have the opportunity to ask for – and receive – all relevant information** concerning the management and treatment of their disease, enabling them to make informed decisions. In particular, patients should be able to request:
  - an appointment with a healthcare professional within two week of their initial diagnosis (if possible).
  - Information on relevant support organisations and services.

<sup>4</sup> My PD Journey: *Experiences reported by people with Parkinson's disease in several European countries – a quantitative and qualitative study* available at <http://www.epda.eu.com/en/projects/my-pd-journey/work-programme/european-inventory/>

## What can the EU do?

Parkinson's represents a serious challenge to the EU's objective of achieving sustainable healthcare systems and promoting 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 more 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 European institutions to take the following steps to help people with Parkinson's disease:

### Five points on how the EU can concretely help people with Parkinson's disease

1. Address the challenges posed by Parkinson's in EU workstreams related to access to medicines, health, long-term and integrated care, as well as in the research and innovation activities to provide the Parkinson's community with new treatments and models for adequate care across Europe.
2. Improve employment conditions, reduce stigma and ensure accessibility to essential services for people with Parkinson's disease in the context of the development of the European Social Pillar.
3. Improve systematic data collection by including up-to-date information on Parkinson's in the '*State of Health in Europe*' cycle, jointly organised by the European Commission and the OECD, which would help to demonstrate the impact of the disease on health systems.
4. Consider developing a model for disease registries for Parkinson's, based on existing good practices at national and regional level, and explore the possibility for the creation of European Reference Networks (ERN), with specific regards to rare forms and advanced stages of Parkinson's.
5. Provide funding through existing programmes for projects that improve the lives of people with Parkinson's and their families, for training on Parkinson's disease for healthcare professionals as well as for scaling up of projects that aims to reduce waiting times for diagnosis and improve integrated care with the help of innovative technologies.

## About the EPDA

The EPDA is the only European Parkinson's umbrella association. It represents national Parkinson's associations in nearly 30 countries across Europe and advocates for the rights and needs of more than 1.2 million people with Parkinson's and their families. The EPDA's vision is to enable all people with Parkinson's to live a full life while supporting the search for a cure. Visit [www.epda.eu.com](http://www.epda.eu.com) for more information.

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 all inquiries about the EPDA's advocacy programme, please contact [advocacy@epda.eu.com](mailto:advocacy@epda.eu.com).