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 disease invariably impacts the physical, cognitive and psychological domains, across nearly every cultural, social and economic boundary.

The disease 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 disease** 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).

The cost of treatment per person with Parkinson's amounts to approximately **€11,000** 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.

Key challenges and unmet needs in the management of Parkinson's disease[2]

There is no diagnostically conclusive test for Parkinson's yet, so the diagnosis is clinical in nature. In the clinical setting, Parkinson's disease is commonly missed or misdiagnosed since many symptoms are also common to other diseases both neurodegenerative and non-neurodegenerative. The diagnosis and treatment of Parkinson's disease 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. Indeed even treatments can lose their effectiveness with time, and often cause unpleasant side effects.

A growing body of evidence from the medical literature describes numerous advantages that may be associated with early therapeutic intervention in Parkinson's disease. Clinical trials also suggest that early treatment can **slow disease progression**. Both the decrease of symptoms and the potential for slowing disease progression,

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[1] European Brain Council, *Costs of Disorders of the Brain in Europe* (2010)

[2] 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)

have a major impact on **improving patient quality of life and reducing the costs associated with Parkinson's in the long run,** as the great majority of costs attributable to Parkinson's occur when the disease is at its most advanced stage and when symptoms are most severe.

Non-adherence is common, critical, and costly in Parkinson's. It presents serious socio-economic consequences and well-being deterioration not only for the patients but also for family members. People with Parkinson's in general 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** may 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 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 MyPD Journey[3], 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 disease healthcare professional who is trained to monitor and manage the disease 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 is significantly improved and monitoring methods be developed*. This will ensure people with Parkinson's care plans remain consistent, regular and cohesive, resulting in their individual needs and preferences being met;
5. *Improved training about Parkinson's for professionals working in nursing homes and general hospital wards is essential*.
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.

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[3] *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/

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 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 more information on its flagship initiatives and activities, please see http://www.epda.eu.com/en/projects/my-pd-journey/.