parkinson's europe

30 wishes

from the Parkinson's community

A Parkinson's Manifesto for Europe

October 2022

parkinsonseurope.org

Parkinson’s Europe (formally the European Parkinson’s Disease Association) was established in 1992 to:

- provide information and education
- advocate for the rights and needs of people with Parkinson’s and their families
- share good practices
- raise awareness

While these four principles remain central to our work, our 30th anniversary is the perfect opportunity to understand and share what the Parkinson’s community feel they need to improve their lives over the next 30 years.

Throughout 2022, we have collected opinions and insights from people living with Parkinson’s in Europe, as well as their caregivers, families and health professionals.

This manifesto is a reflection of their hopes, wishes and ambitions for the future.

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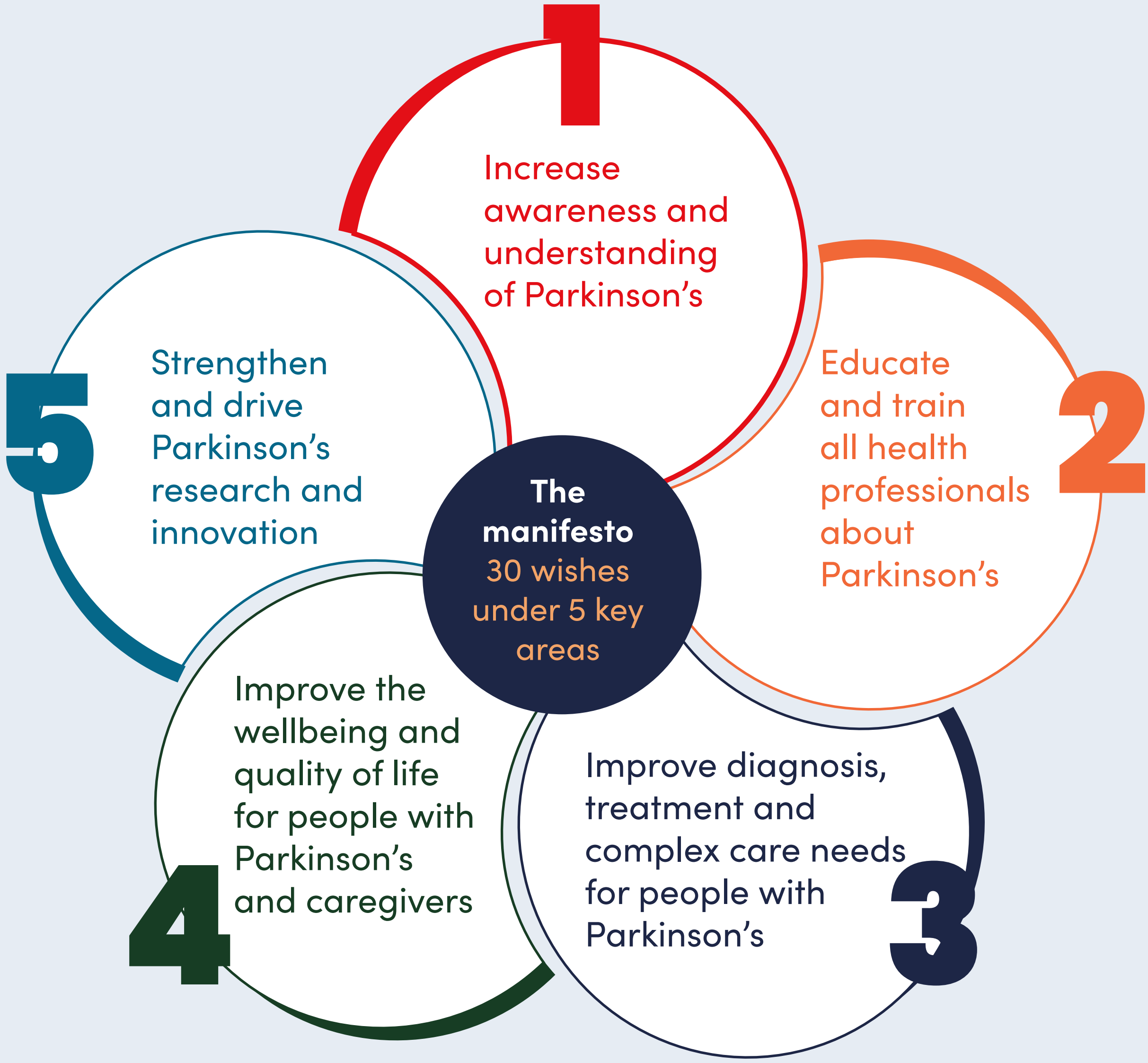

The manifesto 30 wishes under 5 key areas

1 Increase awareness and understanding of Parkinson’s

2 Educate and train all health professionals about Parkinson’s

3 Improve diagnosis, treatment and complex care needs for people with Parkinson’s

4 Improve the wellbeing and quality of life for people with Parkinson’s and caregivers

5 Strengthen and drive Parkinson’s research and innovation

30 wishes from the Parkinson's community

① Increase awareness and understanding of Parkinson's

Key wishes

1. Ensure people with Parkinson's, caregivers and families have the resources they need to aid their understanding and management of Parkinson's
2. Improve all health professionals' understanding of Parkinson's so they can better manage symptoms and support those with the condition
3. Increase awareness among policymakers, politicians and governments to make Parkinson's a public health priority in Europe
4. Raise awareness of Parkinson's among the general population
5. Increase awareness of gender and age differences among people with Parkinson's to create a more accurate representation of the variety of people the condition affects
6. Increase the visibility of new discoveries made through Parkinson's research

> "People genuinely say things about people with Parkinson's like, 'Would you look at that guy, shuffling there – he's so drunk he can't walk and it's only 11.30am!'"
>
> **- Gary Boyle**
>
> Person living with Parkinson's, Ireland

2 Educate and train all health professionals about Parkinson's

Key wishes

7. Ensure that all health professionals have a better understanding and knowledge of Parkinson's as well as improved access to training and education
8. Enable health professionals who are experts in the Parkinson's field to easily share best practice
9. Encourage health professionals to provide a diagnosis in a sensitive, supportive and timely way
10. Ensure that health professionals better understand the needs of the individual by listening to and involving people with Parkinson's in developing personalised care plans
11. Equip health professionals with appropriate resources and tools so they can help people with Parkinson's best manage their condition at every stage
12. Enable health professionals to support the Parkinson's community to connect with research opportunities

> "In terms of better training, the first and most important step is about 'seeing and listening' to patients so we can understand their wishes and desires."
>
> **– Dr Nicola Modugno**
> Neurologist, Italy

3 Improve diagnosis, treatment and complex care needs for people with Parkinson's

Key wishes

13. Improve access to – and increase the number of – Parkinson's health care specialists

14. Increase access to multidisciplinary care systems that offer coordinated care packages and improved specialist technologies, thereby creating a more personalised approach to 'patient' management

15. Provide the Parkinson's community with a greater number of alternative and innovative care and support options

16. Improve communication within health systems and between health professionals

17. Offer clear, timely and consistent access to licensed treatments that provide increased efficacy, better pain relief and fewer side effects, as well as the opportunity to take fewer medications

> "Every patient is unique, and doctors should ask us what we need to live – instead of limiting their service only to prescribe medication. A lot of drugs have side effects and worsen our quality of life. I prefer taking fewer drugs and being able to do the things that make me feel good rather than run the marathon and have to live with all the side effects I don't want."
>
> **- Jannie Strijbos de Krey**
> Person living with Parkinson's, Spain

4 Improve the wellbeing and quality of life for people with Parkinson's and caregivers

Key wishes

18. Support the adoption of a holistic care system that takes into account the whole person: their emotional, physical, mental and social wellbeing

19. Provide better access to and funding for additional therapies such as exercise, nutrition, mental health and psychological wellbeing (including alternative and complementary therapies)

20. Provide more information and support for specialised housing, nursing and respite care

21. Offer more guidance and support throughout the entire Parkinson's journey encompassing all stages of the condition, from diagnosis to end of life

22. Provide more financial and social support for people with Parkinson's and their caregivers, including better support for those still working and managing family life after diagnosis

23. Make it easier for people affected by Parkinson's to connect with others in the Parkinson's community to share experiences and knowledge, thereby addressing isolation and providing motivation and inspiration

"My father has never met or socialised with other people living with Parkinson's. I believe it is vital he gets connected because as hard as we – his family and friends – try, we can never deeply understand how people with Parkinson's feel."

- Alexandra Karadimou
Family member, Greece

5 Strengthen and drive Parkinson's research and innovation

Key wishes

24. Align research goals with the needs and wants of the Parkinson's community – i.e., increasing the focus on finding solutions to daily living challenges, reducing side effects from medications, and accelerating research into genetic and environmental risk factors

25. Improve the Parkinson's community's engagement with and access to research by addressing current barriers and challenges

26. Identify tools that will enable earlier and clearer diagnosis

27. Increase funding for Parkinson's research while accelerating and improving design and delivery

28. Improve communication with people with Parkinson's before, during and after participation in a clinical trial

29. Increase collaboration and data sharing between researchers and innovators

30. Identify treatments that will halt the progression of, reverse and prevent Parkinson's, ultimately providing the steps to a cure

> "In research it is really important to bring together researchers and patients so that the right questions are asked."
>
> **- Veerle Aertsen**
> Young onset Parkinson's Patient, Belgium

What next for the manifesto?

The aim of this manifesto is to help shape the Parkinson's agenda in Europe, guiding those working in health, research and policy on what truly matters to the Parkinson's community. Rather than being a list of actions for any specific organisation (including Parkinson's Europe), the manifesto presents key wishes designed to inspire collaborations and activities for all Parkinson's organisations, groups and individuals across Europe.

Communicating the hopes and ambitions of the Parkinson's community is the first step in our goal to improve the lives of people living with Parkinson's. In order to move from these wishes to a list of potential collaborative actions, Parkinson's Europe's next steps will be to identify the gaps, challenges and areas of good practice relating to each of the key areas outlined in this manifesto.

If you would like to contribute to this work, please visit our website www.parkinsonseurope.org/manifesto and share with us your insights on the gaps, challenges and good practices in your country.

More information

Details on the next steps for this manifesto will be revealed in due course via Parkinson's Europe's website and social media platforms. For further information on the manifesto's methodology and contributors, visit **www.parkinsonseurope.org/manifesto.**

Thank you

Parkinson's Europe would like to thank the 900+ members of the Parkinson's community across Europe who completed our survey and the individuals who participated in our manifesto workshops.

parkinson's europe

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