

Parkinson's Excellence Network: Vision for integrated multidisciplinary care

Our vision

We want all people with Parkinson's to have timely access to best practice, person centred, integrated multidisciplinary care. We want them to have this access no matter their background, identity, circumstances, or where they live in the UK. This means getting the right care from the right expert professionals at the right time.

Care should be coordinated by an expert multidisciplinary team (MDT), with seamless communication between all team members, the relevant health and social care services, the person with Parkinson's and their loved ones. Implementation of this vision will not be easy and we recognise that services are at different starting points and operate differently across the four nations. But the Parkinson's Excellence Network is committed to making it happen. Not in the future, but now.

What does this mean?

1. Right care

- 1.1. There are over 40 symptoms associated with Parkinson's and there is currently no cure. People with the condition are therefore likely to need support from multiple different professionals at the point of diagnosis and beyond. Individuals should be supported by a MDT of health and care professionals with expertise in managing Parkinson's. We recognise that

achieving the right care is not a 'one size fits all' approach. The care that people with Parkinson's receive should be informed by and account for their individual needs, preferences, and the diversity of the Parkinson's community.

- 1.2. Care should be planned and delivered in a person centred way using the principles of shared decision making [2].
- 1.3. The role of the MDT is to proactively create and oversee the implementation of personalised care plans, including a 'rehabilitation prescription', for each individual under their care.
- 1.4. Care plans should be centred around what matters most to the individual. They should be anticipatory and goal focussed [10], and should be reviewed whenever there is a significant change in circumstances or symptoms and at least annually.
- 1.5. Care pathways should be fully integrated across primary, secondary and tertiary care and care plans should be shared across the local health system, including with the person's GP and the ambulance service.
- 1.6. Evidence based standardised assessments and outcomes frameworks should routinely be used to detect and monitor symptoms and levels of independence. We recommend use of the [Non motor Symptoms Questionnaire](#) (NMSQ), the [European Physiotherapy Guideline for Parkinson's Disease](#), the [Lindop Parkinson's Physiotherapy Assessment Scale](#) (LPAS) and the [Royal College of Occupational Therapists guidance for people with Parkinson's](#).
- 1.7. Effective and efficient communication between MDT members is essential. MDTs should have access to the right systems and technology to enable this. The person with Parkinson's should not have to repeatedly explain care needs to new professionals.
- 1.8. People with Parkinson's and their loved ones should be informed about the roles and responsibilities of the MDT and be directed to a single point of contact. Information about Parkinson's should be provided in formats that are suited to the individual's needs and preferences. This could be through a referral to [Parkinson's Connect](#).
- 1.9. Everyone should have the opportunity to [participate in research and clinical trials](#).
- 1.10. Novel ways of working (for example, remote appointments, digital monitoring, virtual MDTs) should be actively explored and embraced but need to take account of the particular needs and abilities (such as digital literacy) of each person and their loved ones. Individuals should be reviewed in person at least once a year.
- 1.11. Early planning for care at the end of life ensures that families and professionals can be made aware of a person's wishes before communication

or cognitive changes make this difficult or impossible. Discussions should be initiated as appropriate (for example, if there has been a pattern of repeated hospital infections or hospital admissions) and should be documented in the personalised care plan.

- 1.12. All MDTs should routinely audit their practice through the [UK Parkinson's Audit](#).

2. Right professionals

- 2.1. People with Parkinson's need access to a core team of professionals with the expertise to assess and support: movement, mental health, cognition, speech, swallowing, continence, work related issues and social care needs (note this list is not exhaustive). The evidence suggests that the best MDTs include the following professionals working together in a seamless manner, regardless of employer, to provide expert care :
- A consultant physician specialising in movement disorders (either a neurologist or a care of the elderly physician)
 - A specialist Parkinson's nurse
 - A physiotherapist with expertise in Parkinson's
 - An occupational therapist with expertise in Parkinson's
 - A speech and language therapist with expertise in Parkinson's
 - A specialist mental health professional, for example a neuropsychiatrist or neuropsychologist
- 2.2. The MDT name may be different in different locations and the name itself is not important. For example, some teams may refer to themselves as the Parkinson's MDT; others may call themselves the Frailty Team or the Neuro Rehab Team.
- 2.3. The contribution of each team member in individual cases will depend on the stage of the person's condition and their needs.
- 2.4. Larger MDTs should have a MDT coordinator to support the smooth running of meetings and coordination of care.
- 2.5. There should also be clear pathways into other relevant services, including but not limited to: neurosurgery, gastroenterology, dietetics, continence services, pain services, mental health services, sleep services, pharmacy, palliative care, community services and social services.

3. Right time

- 3.1. All people suspected of having Parkinson's should be reviewed by a Parkinson's specialist within 6 weeks of referral. If the medical history suggests that the person could be in the later stages of the condition, they should be seen within 2 weeks.
- 3.2. All new cases should be referred to a specialist MDT and discussed at an MDT meeting within 3 months of diagnosis.
- 3.3. Consultant led treatment must be commenced within 18 weeks of referral.
- 3.4. Care plans should be reviewed by the MDT and the person with Parkinson's as required, such as in the event of a new troubling symptom. As a minimum, this must be done annually.
- 3.5. There should also be a mechanism for responding rapidly to significant changes in symptoms or circumstances. People with Parkinson's should be able to trigger an assessment if needed.

Key references and supporting documents

Parkinson's best practice pathways and guidance:

1. Optimum clinical pathway for adults: Movement Disorders (not yet published)
2. Nice Guideline [NG71]: [Parkinson's disease in adults](#)
3. Nice guideline [NG127]: [Suspected neurological conditions: recognition and referral](#)
4. Parkinson's NICE Quality Standards (2018QS164) [Overview | Parkinson's disease | Quality standards | NICE](#)
5. [NHS RightCare Progressive Neurological Condition Toolkit](#)
6. [NHS RightCare scenario](#): The variation between standard and optimal pathways
Sarah's story: Parkinson's Appendix 1: Summary slide pack
7. [NHS RightCare scenario](#): The variation between standard and optimal pathways
Sarah's story: Parkinson's Appendix 2: Short summary slide pack
8. [Parkinson's disease - Symptoms, diagnosis and treatment | BMJ Best Practice BMJ Best practice Parkinson's disease](#)
9. [Bloem B, Okun M and Klein C. Parkinson's Disease. The Lancet \(2021\)](#) - see Appendix 1 for the key figure from this paper
10. [Anticipatory care planning template](#)

Shared decision making:

11. <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>

Palliative care

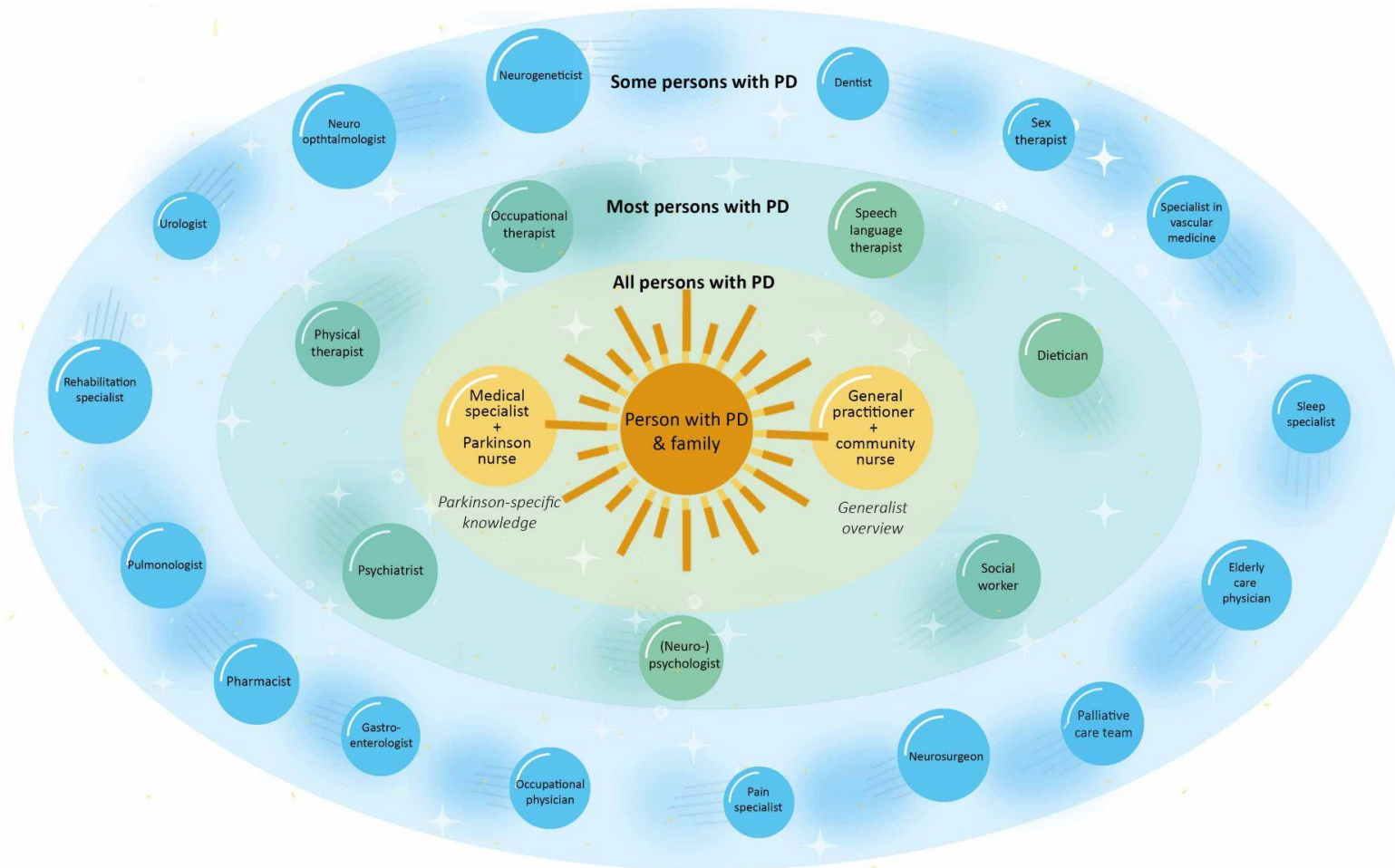
12. <https://www.parkinsons.org.uk/information-and-support/palliative-care>
13. [Parkinson's UK policy statement](#)
14. [End of life care www.england.nhs.uk/eolc](http://www.england.nhs.uk/eolc)
15. www.macmillan.org.uk/.../palliative-and-end-of-life-care

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Appendix 1

Professional disciplines involved in the multidisciplinary care of people with Parkinson's Disease¹.



¹ Bloem B, Okun M, Klein C. Parkinson's Disease. The Lancet (2021). Copied with kind permission from Professor Bas Bloem.