



Pump priming Parkinson's nurse posts

The kickstarting or 'pump priming' of posts by charities has been an impactful way of securing commitment from the NHS for the development of specialist services for a range of conditions. Parkinson's UK has successfully funded and supported over 325 new specialist nurse posts across the UK via the pump priming model. The Excellence Network, with funds from Parkinson's UK, continues to offer funds to pump prime Parkinson's nurse specialist posts.

Why do people with Parkinson's need access to a Parkinson's nurse?

- People with Parkinson's identify that receiving high quality healthcare services is one of their top priorities.
- Access to a specialist Parkinson's nurse is frequently cited as being the most important element of their care.
- The [2019 UK Parkinson's Audit](#) shows that 94% of services have a Parkinson's nurse. Patient Reported Experience Measure (PREM) data demonstrate how highly people value their nurse service: 88% of respondents stated that their nurse service was "Excellent" or "Good".

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“I wanted to stress the difference having access to a Parkinson's specialist nurse makes to my life with Parkinson's. She understands what I'm talking about and discusses medication needs with me in an informed way. She [reads] my notes before talking to me and understands the decisions that we have made previously. She is the only person who seems to monitor side effects and non motor symptoms and she's able to give me options and explain the positives and negatives of these. Most importantly, I am left with the feeling that I have choices which will help me manage this condition more effectively; having the support from a specialist nurse makes me feel that I can keep on top of things. Left with a perfectly nice GP who knows nothing about Parkinson's I had been feeling in total free fall but one brief conversation with the specialist nurse and I feel supported and even slightly optimistic”

Person with Parkinson's

How has Parkinson's UK and The Excellence Network helped develop the Parkinson's nurse workforce?

Between 1996 and 2021, Parkinson's UK pump primed 320 nurse posts and directly invested approximately £8m into developing and supporting specialist nurse posts. The Excellence Network, with funds from Parkinson's UK, continues to offer funds to pump prime Parkinson's nurse specialist posts. But we've not done it alone. Across all four UK nations, we've had support from expert influencers, impassioned local groups and communities, and generous funders. Most notably with recent funding from the Monument Trust and the National Garden Scheme.

In 2001 we set a target of achieving 240 nurses by 2006; at the time, this was thought to be enough to cover the whole of the UK. In 2006 the NICE guideline *Parkinson's Disease in Adults* was published with a recommendation of a caseload of 300 individuals per nurse.

Sadly this was removed from the 2017 guideline due to insufficient evidence. We are actively working on strengthening that evidence base for all parts of the UK. However, we realised that our 240 nurse target was not enough and the goal was changed to say exactly what the charity believed in: **“Universal access to a Parkinson's nurse for anyone affected by the condition.”**

Based on the number of people with Parkinson's currently living in the UK, we estimate that the NHS needs a minimum of 540 whole time equivalent Parkinson's nurses.



We have shown that Parkinson's nurses can enable savings to be made across health and social care services. Timely nurse input results in fewer emergency hospital admissions, reduced hospital length of stay, fewer falls, and improved mobility and independence of people with Parkinson's.

Our figures show NHS investment into a nurse specialist role can, over the course of a year, save:

- £43,812 from avoided consultant appointments
- £80,000 from unplanned hospital admissions
- £147,021 from unnecessary days spent in hospital

Which nurse posts is the Excellence Network open to funding?

We are open to receiving bids for funding to support the development of any new specialist nurse post that is fully dedicated to Parkinson's.

We welcome bids for posts that will truly transform the local service for people with Parkinson's, for example through: better access to integrated multidisciplinary care, improved anticipatory or preventative care, better access to advanced treatments (for example, Duodopa) and better inpatient management.

We prioritise these proposals above ones that are simply looking for an additional member of staff. We also prioritise bids that will produce high quality data and evidence about the benefits of integrated multidisciplinary care and have the potential to inform new models of Parkinson's care across the UK.

Research with our Parkinson's nurse community tells us that around 40% of the current workforce are planning on leaving between 2025 and 2030. We are therefore also keen to work with organisations looking to develop effective models for succession planning.

In deciding which posts to fund, we consider:

- The size and demographics of the local population of people with Parkinson's (we prioritise areas with high levels of health inequality)
- The current level of access to a Parkinson's nurse
- The risks to the local community if the Excellence Network does not fund the new post
- The geography and size of the area that the post holder will be expected to cover, and whether the 'banding' of the new post is justified
- How the post will integrate across community and acute care

The logo for Parkinson's Excellence Network features the text 'PARKINSON'S' in a smaller, blue, sans-serif font above 'Excellence Network' in a larger, bold, dark blue, sans-serif font. To the right of the text is a stylized graphic consisting of a dark blue arrow pointing upwards and to the right, with a light blue curved shape behind it that suggests movement or a path.

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- How people with Parkinson's, our local community networks (including [Parkinson's UK local groups](#)), and local clinicians have been involved in developing the bid
- The financial status of the bidders: will they be able to continue funding the post following our initial investment?
- Whether there are alternative ways to improve services locally that should also be considered

What does the funding cover?

We cover the cost of the creation of **new posts or hours**. Pump priming money is **not** available to cover the replacement of existing posts that have or will become vacant due to resignation, retirement, long term sickness or maternity or paternity leave. The amount of funding available is flexible and depends on local circumstances.

Funding covers the salary, employer pension and employer National Insurance contributions based on the [Agenda for change](#) pay scales. The funding does not cover equipment, administration or bank hours. Please ensure that you have consulted with your local finance team to agree exact costs before submitting your bid.

We believe it is important the local NHS, ICS, health board or trust make a contribution to the post over and above the pump priming money. You must include details of how the local NHS will cover the associated costs (such as administration, equipment, office space and travel) in your bid.

How to apply

Once you have decided that you might like to submit a bid, please submit your expression of interest using the [online form](#). Once received someone from the Service Improvement team will contact you to provide you with more information and talk you through the process.

You will then need to prepare a bid and send it to the Head of Service Improvement and Grants at serviceimprovement@parkinsons.org.uk. The bid must include:

- A business case
- A letter of intent. (This must be signed by either the Chief Executive, Chief Financial officer or equivalent)

Please note that you must have previously submitted an expression of interest [form](#) before you send in your completed business case and letter of intent.

The business case

This should include:

- The aims and objectives of the post
- Details of the desired post: band, hours, amount requested and duration of funding (please remember we only cover salary, National Insurance and pension)
- Details about the service including geographical cover, population, current outcomes
- The clinical case for support (eg, fewer falls, improved timeliness of time critical medications in hospital)
- The economic case for support (eg, improved non-elective length of stay)
- The financial case for support. This should include the costings and an explanation for why you need the Excellence Network to pump prime the post
- An options appraisal: what other options were considered and why is your desired post the preferred option?
- The risks or barriers to developing this post if funding is not granted. You should describe any contingency plans that are in place if The Excellence Network can not fund the post wholly or partly
- How people with Parkinson's have been involved
- How you will audit and evaluate the post

The letter of intent

- This must be from the organisation that will continue the funding at the end of the pump priming period.
- It must be signed by either the Chief Executive, Chief Financial Officer or equivalent
- It should include:
 - The key aims and objectives that will be used to monitor the impact of the post
 - Any key performance indicators
 - The amount and duration of funding being requested

If any of the paperwork is missing or incomplete the bid will be returned.

The decision making process

Decisions are made by the Pump Priming Funding Panel. The Panel reviews bids up to twice a year. The submission deadlines for the Panel meeting are on our website.

The membership of the Pump Priming Funding Panel includes:

- Director of External Relations, Parkinson's UK (Chair)

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- Nurse and Therapy leads of the Parkinson's Excellence Network Clinical Leadership Team
- Associate Director of Policy & Health Strategy, Parkinson's UK
- Head of Service Improvement & Grants, Parkinson's UK
- A lay reviewer (person with lived experience of Parkinson's)

If specific expertise is required for a particular decision, the panel will co-opt additional members onto the panel to support decision making.

What happens if the bid is successful?

Once a final decision is made we will contact the person who submitted the bid to inform them of the outcome.

If successful, a formal letter will be sent to this person by the Chair of the Funding Panel detailing:

- The total amount funded
- Instructions for invoicing
- Information about our proposed ongoing involvement in recruiting and supporting the new member of staff
- Your key Parkinson's UK and Excellence Network contact

Support from the Parkinson's Excellence Network

Our Service Improvement Team can support you in developing your bid. We can support with:

- Information and advice about different service models
- Development of your business case
- Example business cases
- Development of key performance indicators
- Evidence and data, including
 - [Prevalence data](#) for Northern Ireland, Scotland, Wales and England
 - [Hospital Episode Statistics \(HES\) data](#) for Scotland, Wales and England
 - Prescribing data for Northern Ireland, Scotland, Wales and England
- Links to community networks, including [local groups](#) and people with lived experience of Parkinson's

For more information or requests for support, please email serviceimprovement@parkinsons.org.uk.



Appendix

[View the 2024 pump priming timelines](#) (PDF, 87KB).

[Download the business case submission checklist](#) (PDF, 747KB)