



The Parkinson's UK Nurse Appeal

Great care, everywhere





We're investing in great care



Gary Shaughnessy CBE
Chair of the Board of Trustees at Parkinson's UK

I see and hear, day in day out, how important specialist care is for people with Parkinson's. It really can make all the difference to

someone's quality of life, and their enjoyment of the things they love. I hear many powerful stories of this happening. Sadly though, I also hear of the care not keeping up with demand, and the impact on people with Parkinson's and their families of missing out on what we know is possible.

As Chair of Trustees at the charity, I'm delighted that we're prioritising specialist care, aiming to make strides towards there being great care that recognises the needs of the individual, everywhere. Our heritage includes having shaped the Parkinson's nurse role and supported many brilliant nurses over the last three decades.

We are determined to build on this legacy by funding the right roles and support to be there for the needs of all people with Parkinson's in the future. Please join us on that journey and help us make the change we need, together.





Image source: Public Finance

Caroline Russell **Chief Executive Officer at Parkinson's UK**

Since joining Parkinson's UK in 2021, I've seen it as a personal priority to accelerate this critical area of work.

Having worked in senior roles in the NHS, I've experienced first-hand the challenges healthcare is under, and how difficult it can be to prioritise the specialist care we know is needed.

Partnership working between charities like ours and NHS organisations can make a transformational difference. By seed-funding new roles and comprehensively supporting the existing workforce, together we can get significantly closer to ensuring that specialist multidisciplinary care is available in every part of the UK, for every person with Parkinson's.

People with Parkinson's and their loved ones can't wait for great care. With too many people already missing out on the specialist care they need, and 18,000 people being diagnosed every year, we have to act with urgency. Together, we must fund it now.





About the appeal

Every person with Parkinson's should get specialist healthcare. It's a lifeline for those who do get it. But thousands don't. They can't access a Parkinson's nurse or physiotherapist, or get mental health support. They don't have the specialist care that would help them manage their symptoms better, reduce their stress, and live life more independently.

But with your help, we can close the gap. We've successfully seed-funded hundreds of nurse posts, and worked with the NHS to make these permanent.

Give today, and together we can get specialist Parkinson's care to thousands more people

who urgently need it. Together we can fund great care, everywhere.

Great care helps people with Parkinson's live better. It's tailored to each person. Coordinated by a Parkinson's nurse or doctor, with specialists providing joined up support for specific symptoms. And it's available whenever and wherever it's needed.

Parkinson's nurses

Trained specialists with a deep understanding of the condition, they're a continuous point of contact for people with Parkinson's. They help manage medication and symptoms, offer information and support, reduce anxiety around Parkinson's and signpost other sources of help.





Allied health professionals

Allied health professionals include physiotherapists, occupational therapists, speech and language therapists, pharmacists and mental health professionals. They work together with Parkinson's nurses and doctors to provide the treatments and therapies that each individual needs.

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Without any of my Parkinson's nurses, I would not have survived living with the progression of the condition so far. They have been great not just for medication and treatment, but challenging the DVLA on more than one occasion about my driving licence situation, and also helping signpost me into other services.

Simon, living with Parkinson's

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Stretched services

20% of people with Parkinson's in the UK have no or limited access to a Parkinson's nurse.

The current estimated numbers of people with Parkinson's missing out are:

- Northern Ireland: 1,320
- Wales: 1,680
- Scotland: 3,360
- England: 26,550

To address this we need over 100 additional nurses, distributed as follows:

- Northern Ireland: at least 4 nurses
- Wales: 5
- Scotland: 11
- England: 88

Data source: Parkinson's UK analysis, 2024





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Parkinson's nurses and allied health professionals improve the quality of life of people with Parkinson's and allow them to remain independent for longer, reducing the need for intervention from other healthcare areas.

Louise, Parkinson's nurse, Wales

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We are that anchor between the patient and the healthcare system. It's sad to think that some patients don't get access to a specialist nursing team. This resource should be accessible for all. We are the glue that can often keep things together.

Clare, Parkinson's nurse, England

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Although I am quite independent, I would like to have more support from the nursing service to speak about my illness and concerns I have. Appointments are too rushed. I get tongue tied. I get quite a lot of anxiety and find the fast pace of review clinics very pressured and feel that if I could speak with the nurse more regularly I would understand how my diagnosis affects me.

Person with Parkinson's, Scotland

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Waiting lists for neurology are the longest they have ever been in Northern Ireland. We seed-funded the specialist Parkinson's nurses here, but there just aren't enough to meet the demands.

Service improvement manager at
Parkinson's UK, Northern Ireland

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Our cornerstone donor



Frank and Evelyn Brake's story

Frank and Evelyn Brake were both long-standing supporters of Parkinson's UK. Evelyn lived with Parkinson's for over 30 years before sadly passing away in 2022. To continue Frank's legacy since his death in 2018, his Charitable Trust remains a generous supporter.

The whole family's experiences of living with the condition mean they truly understand how vital it is for people with Parkinson's to be able to access the right information and support, at the right time, and in the right way.

The Frank Brake Charitable Trust is the cornerstone donor to the Parkinson's UK Nurse Appeal, and has generously pledged to support the appeal through a donation of £700,000.

We are tremendously grateful for Frank and Evelyn's valued involvement and the Trust's continued support of our work.





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Our whole trustee board, either individually or through families or friends, know of someone who has Parkinson's and what it means to live with Parkinson's. So that's really why it's such an important cause for us. It has touched all of our lives.

We have seen first-hand that a Parkinson's nurse is pivotal to anybody who has been diagnosed. Your nurse picks you up and calms you down, tells you what's needed, where to go and cares about how you are doing. I think they're a lifeline.

The charity has done great work with the amount of nurses they have already funded but more people are being diagnosed and we need to significantly increase the amount of Parkinson's nurses at this critical time. If you're considering making a donation, please do it now.”

Steph Senior
Chair of the Frank Brake Charitable Trust

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Closing the gap

The UK needs over 100 more Parkinson's nurses. That's our vision, but we know we won't achieve it overnight. The Parkinson's UK Nurse Appeal aims to raise £9 million over the next 3 years.

What we'll fund

- At least 25 new Parkinson's nurses, giving 7,500 more people access to a specialist nurse and giving existing nurses more time to support those they already care for.
- At least 30 allied health professionals, giving 12,000 more people expert care for specific symptoms.
- 6 clinical fellowships to support the brightest and best doctors to become the future leaders of neurology and geriatrics services at a local and national level, making sure people with Parkinson's get the best care.
- Extra education and training in Parkinson's care for healthcare professionals.

How your gift will help

- £125 could pay for a morning of specialist nurse time to meet with up to 3 people living with Parkinson's, offering them advice to help them have a better quality of life.
- £15,000 could pay for 3 month's worth of specialist nurse time to meet with 150 people living with Parkinson's
- £50,000 could fund a physiotherapist or other allied health professional post for 1 year, providing expert support as people's Parkinson's symptoms develop.
- £120,000 could fund a Parkinson's nurse post for 2 years, filling a critical gap in services and providing ongoing care for 300 people.



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As my years living with a Parkinson's diagnosis are quickly slipping by, and my symptoms are increasing, I feel like I have no one to turn to when I have questions and concerns about symptoms and changing treatment. It often leaves me feeling a little isolated, as if a key component of my care is missing.

Shafaq, living with Parkinson's

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Louise's story: giving hope



Louise Ebenezer, a Parkinson's nurse
in Bridgend, Wales

I've been a Parkinson's nurse for over 21 years, and it's the most rewarding job I have ever had. I wouldn't want to be doing anything else.

Parkinson's nurses and allied health professionals improve the quality of life of people with Parkinson's and allow them to remain independent for longer, reducing the need for intervention from other healthcare areas.

The knock-on effect

When a patient doesn't have access to a Parkinson's nurse, it often means neither they nor their family fully understand the condition or the variety of symptoms. They won't necessarily have contact with other allied health professionals either, resulting in higher use of other healthcare resources, such as GPs





or emergency departments. But these services aren't specialised to understand and manage Parkinson's symptoms.

Teamwork is vital

Teamwork is the only way forward with Parkinson's. Without multidisciplinary teams, we can't manage the illness. People need to be signposted to the correct professional, whether it's a nurse, a therapist, or social services.

Specialist nurses and allied health professionals are crucial in providing care for people with Parkinson's.

However, for new healthcare professionals entering this field, a significant challenge lies in the need for proper support and mentorship. In the past, I've approached Parkinson's UK to fund a nurse. With their assistance, the new

nurse received comprehensive induction training through seed-funding. This allowed her to acquire skills from various professionals, including neurologists and psychologists.

Donating to the Parkinson's UK Nurse Appeal will help these opportunities become more frequent across the UK. As a result of this seed-funding approach, once the two years are up, new nurses and allied health professionals can hit the ground running. Ready to provide people with Parkinson's great care. Wherever they are.

Patients often tell me that they feel better after they've seen me. We give them hope and we're giving them time, something a lot of people don't do.





Our journey so far

Parkinson's nurses have been playing an essential role in Parkinson's care in the UK since the late 1980s. Since 1996, we've invested more than £15 million into funding, training and supporting Parkinson's nurses.

Fast forward to today and there are over 500 Parkinson's nurses working in the NHS (or around 440 full time equivalent nurses once those who work part time are taken into account). Thanks to the brilliant support of our donors, almost two thirds of these posts were first seed-funded by Parkinson's UK, with the NHS then taking on the ongoing cost.

And we have a 100% success rate of getting the nurse posts we seed-fund sustainably funded by the NHS. Building on the success of this model, we are now able to pioneer new models of care through seed-funding specialist allied health professionals as well.



We are incredibly grateful for the support of the National Garden Scheme, which has been our crucial partner in this work since 2013. They have been pivotal in driving forward our support of Parkinson's nursing and specialist healthcare, donating over £2 million which has enabled us to seed-fund around 20 new Parkinson's nurse posts.



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As the most significant charitable funder of nursing in the UK, the National Garden Scheme is hugely proud to be supporting the Parkinson's UK Nurse Appeal. For almost 100 years, supporting nurses has been at the heart of our charitable purpose. Our commitment to Parkinson's UK has seen £2 million donated to create critical nursing posts since 2013. Working together, we can bring closer the day when every person with Parkinson's has access to the specialist care they need.

George Plumptre
Chief Executive,
National Garden Scheme



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We would also like to extend our gratitude to the Monument Trust and all those incredible donors that supported our original Parkinson's nurse appeal in 2012–2016. Your generosity created a lasting impact that we're continuing to build on.





Jane's story: invaluable support



Jane Hill, BBC journalist and presenter, and supporter of Parkinson's UK

Throughout dad's journey with Parkinson's, mum appreciated his neurologist in Eastbourne and both of them adored his nurse, Louise.

Dad lived with Parkinson's for about 10 years, with symptoms progressing slowly at first. But eventually, the freezing got very bad.

My dad received a formal diagnosis of Parkinson's in 2000, when he was in his mid-60s, retired, and reasonably active. It was mum who had to persuade him to go to the GP, after noticing a difference in his movements. Yet, it took a long time and multiple visits to get an official diagnosis.

Dad's brother had been living with Parkinson's for years. He had a tremor, unlike dad, who froze when he walked. It's a reminder of how different symptoms can be, even within one family.





At that time, Louise was the only Parkinson's nurse for the whole area of East Sussex. Yet she provided invaluable support from early on, with mum saying: "It just felt like she was always available".

Mum often praised Louise's availability as well as her extensive knowledge. She felt it was sometimes as good as talking to the doctor because Louise had such a wealth and breadth of experience. She also frequently said how patient Louise was with my dad, and that she really listened to him, and really understood what was going on.

Dad passed away at 77. After his death, my brother and I realised how challenging the last years had been for mum. She's usually a chatterbox, but whenever I'd ring up she just didn't have the energy to chat for very long – and I used to think, wow, this is really out of

character. So I knew things were difficult, and that she was drained.

That's why I think Parkinson's nurses, like Louise, are vital. Mum says: "I don't know what we'd have done without her." Her constant support and patience were invaluable. In mum's eyes, Louise deserves an OBE for her dedication.





Let's fund great care, everywhere

Parkinson's is the fastest growing neurological condition in the world. In the UK alone, 153,000 people have the condition. As the population ages, this will only increase.

It's time to ramp up our efforts to meet the growing need for specialist Parkinson's care. Great care helps people with Parkinson's live better. Helps them manage their symptoms better, reduce their stress, and live life more independently.

But we need more Parkinson's nurses. We need more allied health professionals. And we need them now.

Together we can get more people the care they need and deserve. Together we can improve the lives of people with Parkinson's and their friends and families. Together we can fund great care, everywhere.




Donate and you will help fund great care, everywhere.
You can scan the QR code or donate online at
parkinsons.org.uk/nurse-appeal





We're Parkinson's UK,
the charity that's
here to support every
Parkinson's journey.
Every step of the way.



Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm, Saturday 10am to 2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
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Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).
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