

# Education with impact: Parkinson's Academy

Learning captured from workplace projects 2022-23





### Introduction

Parkinson's Academy, now in its third decade, has supported over 2,927 healthcare professionals across 83 courses, and seen over 500 workplace projects. Every year, the impact of this long-standing course can be seen in the work taking place at a grassroots level. Sometimes there is a strong and consistent theme, like in 2021 when almost half of the projects focused on bone health, resulting in our report 'Supportive skeletons: addressing bone health in Parkinson's to improve outcomes'.

'Our participants are hands-on clinicians who want learning that helps them to help their patients, and each of this year's projects demonstrates this in action.

These workplace projects give a space for the MasterClass's challenging learning outcomes to change things at a grassroots level and then to keep changing them - and this is what makes a difference to people with Parkinson's'.

Dr Peter Fletcher, academic director

In our MasterClasses spanning 2021-2022, the breadth of project work shed a great deal of light on the variety of challenges facing people with Parkinson's and the services supporting them, highlighting themes of importance. This year, though, the most common project type was a review, audit or evaluation of a service as a whole, and how it meets all of a person's complex needs

Preventative management such as addressing bone health and drawing on physical activity sat alongside addressing orthostatic hypotension to reduce falls. Other thematic care showed the importance of cross-departmental communication, such as in cognitive decline and dementia, palliative care, and timely medication during in-patient care.

'The astounding range of priorities being focused on really shows the complexity of Parkinson's and the determination of those caring for people with the condition to get things right, to treat their whole selves, and to give them the best experiences of healthcare as they can. Our delegates are an inspiration to us - and hopefully, through this report, they will be to you, as well.'

Daiga Heisters, head of Parkinson's Academy





# Responding to needs: is it time for an upgrade?

Whilst a whole host of different specific service elements and care needs were covered by project work this year, by far the most common project approach was to review current services in light of changing requirements and shifting healthcare landscapes, and to remodel services to be fit for purpose in this new environment.

The stand-out project amongst the seven which did this was by Emily Scotney, a Parkinson's clinical specialist. Awarded runner up for her work, she wanted to reflect the NHS agendas for increasing personalisation and reducing outpatient activity by remodelling her services' existing clinic to reflect existing capacity and provide responsive care to people's needs. Using logistics planning and population stratification, Emily and her team devised a way of working differently combined with new interventions including a telephone helpline, patient initiated follow-up, and various types of patient-facing information to meet the needs of patients within existing resources.

Neuropalliative fellow Dr Elisabeth Wilson evaluated a Parkinson's Hub outpatient service designed to support rapidly deteriorating patients or those with atypical symptoms. She found that those patients seen in the clinic had lower rates of unplanned hospital admissions compared with those expected prior to their review. The clinic has also facilitated joint working and referrals with palliative care and the wider multidisciplinary team, as well as supporting patients to discuss advance care planning and RESPECT forms.

Specialist physiotherapist Christopher Dyer wanted to support Parkinson's patients within his district hospital which is supported via a 'spoke' within a hub and spoke model. Almost half of those admitted as in-patients have Parkinson's with no dedicated consultant or neurology nurse to support them or the ward staff. He therefore set up a Parkinson's specialist interest group, developed training for in-patient therapy teams and is now looking to initiate a pathway which flags Parkinson's patients on admission.

Geriatrician Dr Glesni Davies ran a full-scale audit and reviewed qualitative and quantitative data to create a full reform of the Parkinson's service she works in. From additional clinics and multidisciplinary meetings to shared inboxes and new posts recruited to, the service is evolving to meet the changing needs of the local population.

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# **Preventative management**

The prevention agenda has been firmly in place within the NHS since the Long Term Plan was published in 2019. In Parkinson's this might mean optimising existing function, such as through lifestyle modification to preserve brain health or exercise to manage symptoms and maintain function. It might be reducing risk, such as improving bone health and managing symptoms to reduce falls, or avoid frailty.

Our report 'Supportive skeletons', arising from a high volume of projects focusing on bone health in 2021, sets out the complex relationship between Parkinson's symptoms and medication, bone density, fractures, falls and frailty, and explains why assessing and managing bone health in people with Parkinson's is essential to improve their outcomes.

This year, geriatric speciality doctor Joshua Drake was awarded runner up for his work looking at how well bone health was being assessed in people with Parkinson's within outpatient clinics at his local hospital in Portsmouth by searching retrospectively for mention of bone health assessments, FRAX calculations and falls history in a random selection of patients across a single month. His findings were encouraging but highlighted there was no systematic approach, so he has developed a clinic proforma with a dedicated section on bone health for future use.

Other projects relating to bone health included geriatrician Dr Deeksha Sangers' work to develop a Parkinson's clinic checklist to ensure bone health is discussed routinely with patients, whilst Dr Athina Angelopoulou reviewed the correlation between fracture risk and malnutrition and / or vitamin D deficiency in cohorts of male and female Parkinson's patients. Her findings confirmed the correlation and triggered education to GPs, liaison with dieticians and improvements in reviewing vitamin D levels in Parkinson's patients.

Another factor increasing risk of falls is orthostatic or postural hypotension, and managing this symptom effectively can also halt the downward cycle of falls and frailty. Both Dr Victoria Stiebel in her New Zealand clinic, and Dr Muhammad Ibrahim in the East of England, reviewed their management of orthostatic hypotension. Finding a significant proportion of patients with OH and Parkinson's had been hospitalised owing to falls, many of which had considerable consequences, the projects suggested that improving routine assessment for OH combined with deprescribing where possible, are important preventative measures.





# Timely access to medication

In hospital settings, people with Parkinson's often do not get their medications on time with anywhere up to 120 minute delays in administration, resulting in worsening symptoms, longer stays, poorer outcomes and greater demand on services following that episode.

The years' winning project, since acknowledged in Scottish parliament and shortlisted for the 2023 Nursing Times awards, was led by specialist nurse Nick Bryden. Through a collaboration with colleagues in digital services and pharmacy, he initiated innovative use of existing electronic systems to improve awareness, education and management. Combining existing e-prescribing with the wards' digital whiteboard technology allows Parkinson's patients to be managed, monitored and audited regarding their medication across different departments, while visual prompts highlight patients who are due or overdue their medication. The initiative, now rolled out across all the NHS Arran and Ayrshire hospitals, has resulted in up to 87% of people with Parkinson's in targeted wards receiving time-critical medications 'on time' (in line with NICE guidance).

Also making use of electronic services was Dr Kerri Ramsay, who liaised with her medical director to get electronic alerts set up for when a person with Parkinson's is admitted to hospital. She then initiated a virtual ward round and created a proforma to be completed for anyone on ward with Parkinson's. The system allows for remote medication reviews, auditing of prescribing, and has supported staff education.

Other projects addressing timely medication were by Parkinson's specialist nurse Moira Whitlock, and Associate specialist Dr Balkumari Gurung. Moira initiated a 'Link nurse' programme in her local hospital, recruiting and supporting 15 ward nurses in ongoing training and peer-support to develop knowledge of Parkinson's, become advocates on the wards, and link with the specialist team. Balkumari carried out a survey of junior doctors to understand what the challenges in timely medication access were and where to focus efforts to improve.

Outside of the in-patient setting, timely access to the best form of medication remains a priority, and Kelley Storey's project focussed on addressing motor complications through appropriate access to complex therapies. The clinical specialist disseminated use of the 5-2-1 tool (p22, non-oral therapy pathway) amongst internal and regional clinicians, introduced a complex therapies multi-disciplinary team meeting for all patients being referred for consideration of advanced therapies and reviewed the Duodopa inpatient pathway to try and minimise unnecessary inpatient stays.

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# Joined up care and cross-departmental conversations

From shared management and multidisciplinary care in Parkinson's generally to specific cross-departmental collaboration needed for key points along a person's individual journey, projects exploring forms of joined-up care are increasingly common. This year we saw examples of this to support cognitive decline, improve recognition of dementia with Lewy bodies (also known as Parkinson's disease dementia), and in medicines management.

Dr Gregor Russell was motivated by an awareness that there is a national underdiagnosis of dementia with Lewy bodies (DLB) in the UK and that often people with this initially present to memory services rather than to specialists in Parkinsonian conditions. He reviewed diagnosis rates in his area and found them half what he would expect from prevalence data. Through a series of conversations with different departments, he initiated use of assessments more likely to identify DLB. As a result, the majority of memory staff agreed to use the DIAMOND-Lewy toolkit in routine memory clinics, toolkit owners gave him permission to adapt DIAMOND-Lewy for local electronic services and then the chief clinical information officer agreed to develop this. He obtained data on DaTSCAN use and asked supervising senior psychologists in the memory service to pilot use of the ACE-III for a six month period.

For specialist nurse Gillian Finlay, there were issues in sharing information across Parkinson's and psychiatry teams as they relied on copies of clinic letters being used for referrals which often resulted in incomplete information being shared, causing delays in patient appointments. She initiated a referral procedure containing all relevant information and streamlining communication across departments, ensuring patients are seen in a timely manner.

In a complex condition such as Parkinson's, collaborative management across the full multidisciplinary team is essential. A pharmacist is a valuable addition to this core MDT given the importance of tailored medication, and the individual nuance this requires. Geriatrician Dr Jawad Ali scoped out the potential need and benefit of a specialist clinical pharmacist being added to the Parkinson's team and found this role would enhance safety, boost cost-effectiveness, would link across primary and secondary care and be 'crucial to providing better patient-centred care'.





# Top tips and takeaways

Here are some ideas you could consider replicating based on this project work, centred around five statements made by the delegates.

- 1. With Parkinson's prevalence rising sharply and NHS services stretched, a review and reshape of services could be needed. Examples in this report include:
  - auditing current services to find out what is working well and what could work better, then making a long-term plan like Glesni Davies or come up with a whole new way of working like Emily Scotney
  - looking at ways to support patients without a specialist consultant or nurse like Christopher Dyer, such as increasing education and setting up a special interest group
- 2. Most patients with advancing Parkinson's report being unsatisfied with their current treatment and not being informed about advanced treatment options. To address this, you could:
  - disseminate the 5-2-1 tool to improve education of when to consider a complex therapy like Kelley Storey did
  - review your pathways in line with the non-oral therapy pathway to improve assessment and access
- 3. A third of hospital admissions for people with Parkinson's are due to fractures so reducing risk of falls, fractures or frailty is important. Ways to do this might include:
  - adding something about bone health into routine Parkinson's clinics via a proforma, like Joshua Drake, a checklist like Deeksha Sanga, or routine use of something like the FRAX tool to assess fracture risk.
  - checking that you regularly monitor patients for orthostatic hypotension and embed it into routine practice like Victoria Stiebel and Muhammad Ibrahim
- **4.** In hospital settings people with Parkinson's often do not get their medications on time. To improve timely access to medications in your hospital and reduce poor outcomes in patients, you could:
  - use existing systems to flag patients and improve administration or monitoring of timely medication like Nick Bryden or add a virtual ward round like Kerri Ramsay
  - replicate Moira Whitlock's 'Link nurse programme'
- **5.** Joined up care leads to better patient outcomes and better staff experiences. Some of the ideas from these projects include:
  - looking at how and where non-specialist services can benefit from learning or support such as Gregor Russell has done in linking with a memory clinic
  - establishing a set referral form, pathway or procedure, like Gillian Finlay

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### Neurology Academy: education with impact

Parkinson's Academy is part of Neurology Academy.

Neurology Academy is an innovative educational provider for healthcare professionals including consultants, specialist nurses, pharmacists, therapists and other allied health professionals. Our courses are developed by practising specialists who combine their experience and expertise into case-based learning designed to create specialists in their field with confidence in effecting change.

We specialise in education, networking and mentorship, encourage the sharing of good practice, and promote clinical leadership across a range of conditions. Each condition or healthcare theme has its own 'Academy'.

### www.neurologyacademy.org

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