



Education with impact: Parkinson's Academy

Learning captured from workplace projects 2023

Introduction

This year's Parkinson's intermodule projects were varied in their themes and wide-ranging in their approaches, with a greater emphasis on personalisation, supporting and managing non-motor symptoms like speech and cognition, and a renewed energy around bone health promotion and preventing unnecessary frailty, fractures and falls.

There was a continued focus on access to time-critical medications, but this year there was a far broader approach to finding solutions, incorporating education, electronic systems, and new ways of working.

There was clear evidence of delegates learning from others' experiences, drawing on successful service improvements elsewhere in the country and applying these models to their localities, from general concepts around bone health assessments and a virtual in-patient liaison service, to the very specific clozapine clinic modelled on the Parkinson's service in Newcastle upon Tyne.

'I have been privileged to witness more than twenty years of project presentations, and this year I was struck by how many work-based projects were building on the learning of those from previous years. Replicating or adapting something that has been tried and tested elsewhere really demonstrates organic and evolving learning within the Parkinson's community.'

Dr Peter Fletcher, academic director

'I really enjoyed how collaborative so many of these projects felt; there was a real sense of using everyone's skills and abilities in a given service to maximise impact for patients. I also noticed that many projects were not complete, but rather the beginning of a longer journey. I think this is positive and will create lasting, sustainable change; I'm looking forward to following up with these projects in the years to come.'

Daiga Heisters, head of Parkinson's Academy

As with our previous 'education with impact' reports, we have ended the report with a summary of ideas to try in your own service, all taken from these delegates' experiences. From offering a form of self-reporting for patients to direct their own clinic appointments, to providing family and friends in caring roles with adequate support when a loved one is living with dementia as part of their Parkinson's, there are a number of ways, both big and small, that you might be inspired to improve your own services in the year ahead.

Reducing frailty, fractures and falls

Over the past several years, there has been a consistent pattern of increasing focus on frailty and falls prevention and bone health promotion in people with Parkinson's. There has been increasing understanding of the complex interrelationship at play across symptoms, medications and side-effects, and between fractures, frailty and falls ([Neurology Academy 2022](#)). Every year we see more and more projects addressing some aspect of these interwoven areas of management and these five projects carried out by Advanced delegates provide new ways of doing this.

Awarded runner up for his work, [consultant geriatrician William Davison](#) cited the British Geriatric Society's '[Fit for frailty](#)' guidance as his impetus to consider using frailty, not age, as a triage criteria for Parkinson's referrals into neurology or older people's medicine. He reviewed 2022-23 patient data for neurology and older people's medicine across age, co-morbidity or multimorbidity, and frailty using the [Rockwood clinical frailty score](#). Generally, he found that frailer and multimorbid patients were usually directed to older people's medicine, but he hopes to add frailty to the triage criteria and routinely assess all people with Parkinson's for frailty across both departments.

Some delegates' projects were kicking off a journey into bone health improvement, whilst others were further down the road. [Elderly care consultant Emma Lines](#) in East and North Hertfordshire audited fracture risk assessment in her elderly care department and found it was not routinely taking place. Meanwhile, [geriatric registrar Dr Jasmine Hart](#) carried out a similar retrospective analysis on a random patient sample in Dundee and found no documented [FRAX scores](#) and that 60% met [NOGG criteria](#) for bone density scans but had not had one. Jasmine noted the importance of looking at the [BONE-PARK algorithm](#) alongside FRAX to ensure Parkinson's patients' score calculations are not underestimated. She has committed to developing a standardised approach to this in the future.

[Parkinson's specialist nurse Sharon Prendergast](#) looked at bone health assessments across neurology, geriatrics, and specialist nurse clinics and found that very few were being carried out. Where they were, they were not being acted on. She plans to use team meetings and protected learning time sessions to educate colleagues and GPs on the importance of assessment, and is liaising with the integrated care board (ICB) to ensure assessments are acted on.

[Parkinson's specialist nurse Grace Hogan](#) has been working towards getting 100% of Parkinson's patients bone health assessments as part of the [Parkinson's Excellence Network bone health improvement](#) initiative. Her project, an audit of this, found that routine assessment and closer working with the osteoporosis nurse and GPs, as well as increased lifestyle advice and information and raising awareness of bone health across patients and staff has all had significant impact. Patients are proactive in seeking advice and updating their treatment plans. There has been increased numbers of bone density scans, increased levels of physical activity noted in patients, and reduced numbers of falls in patients referred to neuro-rehab or having had equipment fitted at home to help with mobility.

Personalising care

There were a number of projects that, whilst addressing different aspects of care, all had something essential in common - a drive towards personalising that care in different settings and spaces. From specific advice and guidance pathways to optimising assessments, developing patient-reported questionnaires and considering when to initiate conversations around lasting power of attorney, a number of delegates used their projects to tailor their services more closely to their patients' needs.

Two delegates focussed on making sure they were capturing symptoms from their patients' perspectives, with [clinical nurse specialist Nicky Stapleton](#) creating a self-reported motor symptom questionnaire after realising remote assessments left her without a clear understanding of the persons' movement experience. Meanwhile [geriatric medicine registrar Su Lee Aung](#) introduced the [PD-NMS questionnaire](#) for patients to complete pre-clinic, and audited symptoms discussed before and after its use. Many symptoms were already being discussed, but she noticed an increase in some topics including salivation and swallowing, pain, sex, vision and sweating.

[Katherine Taylor](#), a [Parkinson's specialist nurse](#) who was awarded 'runner up' for her work, reviewed information on lasting power of attorney (LPA). Informed by recent research finding only one quarter of people with Parkinson's in her service had an LPA in place, she led her team in reviewing and implementing information on LPAs across the whole of the patient journey from their welcome letter onwards. She also rolled out training to staff on LPAs and having conversations about them. Early feedback from patients is positive, and the team is now looking at putting an electronic prompt and tracking option for conversations across clinics.

Also considering information access, [care of the elderly registrar Peter Sugden](#) was aware that people with Parkinson's were often sending 'unscheduled' emails to the movement disorders team seeking advice or information. Mapping emails for a month, he found 30 hours' work had been needed to respond to or action these across the movement disorders team and that the majority had needed professional input or referrals into other services. He proposed that a formal guidance and advice service be established to provide this necessary support to patients as and when they need it, with input across the whole multidisciplinary team.

[Elizabeth Taylor](#), [lead specialist nurse for the movement disorders team](#), initiated a remote assessment clinic for newly-diagnosed Parkinson's patients to maximise resources for the team and ease of access for the patient. She audited people's experiences of the clinic and found 100% to be happy with the format and the assessments and questionnaires used, although a few people struggled with communication, highlighting that there must be space for face to face appointments as needed.

Care for cognition

For people with Parkinson's, mild cognitive impairment is a common symptom in early disease affecting around 40% of people with Parkinson's with more than 80% going on to develop dementia in later stages (Fang 2020). Additionally, people with Parkinson's are at a higher risk of developing a form of Lewy body disease (LBD); one study found an overall incidence in people with Parkinson's of 3.5 for dementia with Lewy bodies (DLB) and 2.5 for Parkinson's disease dementia (PDD), with both increasing steeply with age (Savica 2013) although recent reviews have suggested that diagnosis rates of both are lower than expected (Kane 2018).

Recent years have seen improvements in awareness of cognitive impairment, and improvements in LBD diagnostic criteria with clarity around the differences between DLB and PDD, yet these improvements in diagnosis present new challenges for clinical practice from information and support provision to medicines management.

With a growing awareness of how many people with Parkinson's would be experiencing cognitive impairment or dementia in her area, Parkinson's disease specialist nurse Rebecca Mitchener decided to see whether appropriate support was being offered to family and friends in a caring role. Carrying out a simple survey mapping peoples' experiences against NICE guidance, she found that whilst most had been given basic information on the type of dementia (PDD or DLB) and local support groups at the point of diagnosis, none had received ongoing support, training or information as set out in NICE (2018, 1.11.1-2) around developing living or communication strategies, adapting to behavioural changes, prioritising their own health and wellbeing, or future planning.

A common and challenging symptom of LBD is hallucinations and psychosis, and whilst clozapine has been found to be most effective in reducing its impact in people with Parkinson's, the monitoring requirements and prescribing access via mental health trusts are often barriers to access. Neuropharmacist Derek Weidner, having learned about neurologist Dr Neil Archibald's model for prescribing clozapine directly within his Parkinson's service, explored the feasibility of establishing something similar at St Georges'. He has established a multidisciplinary pilot clinic able to take up to five referrals from a Parkinson's wellness clinic where the patient is registered with a psychiatrist. Beyond five referrals, Derek notes that a business case will be needed to formalise the clinic.

Supporting speech

Parkinson's can cause difficulties with speech and swallowing due to weakening muscles or because of neurological damage itself. Dysarthria, referring to speech difficulties as a result of muscle weakness, can cause hypophonia, or voice quietening, and dysprosody - vocal bradykinesia. Other speech difficulties caused by damage within the brain can also affect people with Parkinson's, such as disfluency or neurogenic stutter. Two delegates worked to improve 'people with Parkinson's' access to speech and language services for these symptoms in very different ways.

The winning project for the Parkinson's Advanced MasterClass this year was a service evaluation of a Lee Silverman voice treatment (LSVT) service within speech and language in London. Prof Carl Clarke recently shared [real world evidence](#) that LSVT is the only meaningful treatment for hypophonia in Parkinson's and [highly specialist speech and language therapist Rebecca Evans](#) evaluated her own LSVT service through data and process mapping. She found problems with long waiting times, low referrals and unclear pathways for professionals to follow. Using a driver diagram, Rebecca identified multiple primary and secondary drivers for change and six ideas for change which would meet these drivers and resolve the challenges she identified, including a number of internal training programmes and developing a clear service pathway.

[Speech and language therapist Stine Brubak](#) is based in Norway. He focused on increasing awareness, identification and subsequent support for Parkinson's patients with a neurogenic stutter, a form of disfluency found in around one fifth of people with Parkinson's ([Gooch 2023](#)). Stine, in order to establish stronger referrals to speech and language, decided to increase awareness of the need first. He reached out to hospitals and service networks to understand levels of awareness around Parkinson's and neurogenic stuttering, and to provide education. Using a short four-question survey, he found that people's understanding of both Parkinson's and neurogenic stuttering increased post-education.

Medication management

The importance of access to time-critical Parkinson's medications whilst in hospital has been the focus of campaigns and awareness-raising for decades, yet it remains a challenge ([Parkinson's UK 2023](#)). Every year, we see projects working in new and innovative ways to address this issue and this year has seen fresh ideas to improve medication access on the wards. Two projects reviewed their current practices and made changes to improve outcomes, whilst one project piloted a virtual in-patient liaison service.

Geriatric consultants [Geetanjali Khullar](#) and [Anthony O'Sullivan](#) both audited medication access in their respective hospitals. Geetanjali carried out a retrospective analysis on a random sample of 30 Parkinson's patients over a six month period, whilst Anthony reviewed seven consecutive days of electronic data alongside the results of a survey to junior doctors on acute and general medicine wards. They both found significant rates of late or missed doses and an apparent lack of understanding over medicine administration routes (e.g. transdermal patches and nasogastric tubes). Both advocated for increased training and awareness within their hospitals. Anthony also suggested a number of other changes, from enabling self-medication for patients who are well enough to do so, to opening two-way lines of communication online between junior doctors and consultants, to planning ward medication stocks so that no doses are missed due to availability.

Consultant physician [James Reid](#) wanted to improve the overall care and support for people with Parkinson's in hospital, of which medication access was one part. He scoped out the requirements for a virtual in-patient liaison service using a weekly virtual multidisciplinary team (MDT) meeting alongside existing IT systems to identify patients needing face to face review. He piloted the service by himself to understand time requirements and gauge the success of using the IT systems, and outlined the time commitment needed from the MDT. He found that the pilot worked well, but that certain red flags should automatically trigger a face to face appointment including changes to medication management, surgical needs, palliative care requirements, and psychosis or delirium.

Top tips and takeaways

Here are some ideas you could consider replicating based on this project work, summarised in five statements made by the delegates themselves, or featured in recent policy and guidance.

1. Improving bone health to reduce falls, fractures and frailty is an important part of preventing worsening outcomes. There are lots of ways to begin addressing this, or to improve on existing initiatives. You could:

- initiate or audit fracture risk / bone health assessments like [Dr Jasmine Hart](#) or [Sharon Prendergast](#), making use of tools like the [BONE-PARK algorithm](#)
- take a multi-disciplinary approach to bone health involving GPs and equipping patients with lifestyle advice and increased awareness like [Grace Hogan](#)
- use frailty as a measure of the best service and support for a person by adding frailty to the triage criteria like [William Davison](#)

2. Everyone's Parkinson's is different, so their care needs to be personalised too - but there are lots of challenges to this. You could think about making one or two small changes to increase your personalisation like:

- offer patients a form of self-reporting symptoms to highlight what they most want to talk about in clinics, like [Nicky Stapleton](#) and [Su Le Aung](#)
- think about making small changes to services, perhaps introducing a remote assessment clinic like [Elizabeth Taylor](#) or a dedicated telephone advice service like [Peter Sugden](#)

3. Mild cognitive impairment and forms of Lewy body disease affect a significant number of people with Parkinson's. Using ideas from this years' projects, you could:

- ensure adequate ongoing support and education to family and friends in a caring role, like [Rebecca Mitchener](#)
- look at other service models to get around prescribing difficulties and trial one locally, like [Derek Weidner](#)

4. There are always more ways to improve timely access to medications on wards. Some of the takeaways from this year are:

- check understanding with a survey and meet educational needs in-house like [Geetanjali Khullar](#) did
- use electronic systems as an informal means of communication between junior doctors and consultants like [Anthony O'Sullivan](#) suggests
- consider a virtual in-patient liaison service like [James Reid](#)

5. Equitable access to services is so important, but enabling this often calls for a variety of solutions. Some of the ideas from these projects include:

- use education to raise awareness of the symptom and the service available to increase referrals, like both [Stine Brubak](#) and [Rebecca Evans](#) did
- establish a clear service pathway like [Rebecca Evans](#)



Neurology Academy: education with impact

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