

# Final category: 1 Innovation in practice

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***A Collaborative approach in utilising existing NHS digital systems in novel ways to improve timely administration of Parkinson's Medication in hospital.***

Nicholas Bryden<sup>1</sup>, Richard Cottrell<sup>2</sup>, Michelle McLuckie<sup>3</sup>

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## **Abstract**

### **Objective**

In NHS Ayrshire and Arran, people with Parkinson's were not getting their medication on time in hospital, causing longer stays and adverse events. Specialist Parkinson's nurse Nick Bryden, Richard Cottrell (Electronic prescribing and pharmacy) and Digital Services identified opportunities to tackle this problem:

- improving ward staff's understanding around the time critical nature of Parkinson's medication
- using existing technologies in new ways, creating effective, sustainable ways to monitor and administer medication across departments.

### **Intervention**

Collaboration across specialist nursing, pharmacy and digital services resulted in novel combined uses of existing electronic systems alongside development of targeted, flexible and varied staff education.

Across three phases, and at no ongoing cost to the Board, the project now:

- enables Parkinson's patients' medications to be managed, monitored and audited on a daily, weekly and monthly basis across all departments (since 2015)
- uses dynamic visual prompts using the existing whiteboard system, to flag patients due their medication, alerting when they are outside the 30 minute time-critical window (since 2018)
- Provides a dashboard for live auditing of medication administrations

### **Results**

Educating and engaging ward staff with this work has encouraged ongoing, grassroots education.

Since beginning the initiative there have been clear improvements in both the proportion of timely administrations given, overall reduction in time between scheduled and administered time of medications, improved patient satisfaction, increased staff education and more effective working.

- Up to 87% of people with Parkinson's in targeted wards now receive time-critical medications on time or within 30 minutes (in line with NICE guidance)
- 64.7% have received medication on time Board-wide in the last 12 months
- Since 2015 timely administration medication has increased Board-wide by 19%

- Reduction in missed doses of Parkinson's medicines through use of tools in refining ward-held stock
- Patient feedback confirms satisfaction and confidence in staff during hospital admissions

Collaboration and information sharing across departments via the monthly administration audit has:

- led to increased training requests
- increased effectiveness of working with minimal cost resource to initiate and no ongoing costs

### **Outcomes**

The initiative has been rolled out across the whole of NHS Ayrshire and Arran (barring emergency department using paper systems); the greatest benefits identified have been:

- For patients: the Whiteboard icon, nicknamed "the tulip" which prompts staff that medication is due. A wards whiteboard was recently broken and their percentage dropped from 82% on time to 72% in just a month. This initiative is low cost, requires low to no resourcing to implement, minimal training to use, and could be utilised across the NHS where HEPMA systems are present, to improve access for all patients requiring time-critical medications; the team hope to share it widely to encourage this.
- For the Parkinson's nurses: the daily report detailing where the patient is, what and for when medication is prescribed, time administered and how timely each dose is. This allows targeted support and education to wards who struggle and awareness of patients who are in hospital.

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## **Time Critical Medication: A quality improvement approach**

Lynne Osborne, Luke Huntly, Kylie Lock, Jacqui Chamberlain  
Cornwall Partnership Foundation Trust, Cornwall, United Kingdom

### **Abstract**

#### **Objective**

In March 2021 Cornwall Partnership Foundation Trust set out to ensure people with Parkinson's received their medication within 30 minutes of the prescribed time within our inpatient community hospitals. This was through an innovative approach in combination with the Life Quality Improvement System.

#### **Intervention**

One pharmacist initially began by engaging with 1-2 community hospital wards, supporting staff in an informal way to understand the importance of Parkinson's time critical medications. From this our core Time Critical Quality Improvement Team comprising a Consultant Nurse, two Pharmacists, a Parkinson's Nurse and Quality Lead began. Other healthcare professionals such as Pharmacy Technicians and acute Parkinson's Nurses join our meetings as required.

Weekly reports were initially created from prescribing data and disseminated via email to our pilot community Hospital wards. These contained data tables and visual charts to illustrate how far away from the 30-minute window medication was being taken. Bite size educational video links within the email combined with the development of ward based posters with QR codes, helped this project gain momentum with more wards coming onboard.

The weekly ward reports are now colourful and continue to easily break down the data highlighting how far away from the 30-minute window medication has been administered. The report goes further showing whether wards have achieved gold or silver status for their efforts. These wards are then rewarded through the organisations WOW Awards.

We are also supporting the Medication Management Link Nurses for each ward area and during 2023 World Parkinson's day provided each ward with a P UK washbag containing a pill timer rememberer along with specific booklets / information. This has enabled us to bring our key Mental Health wards into this project, bringing us to 16 wards over 9 different community hospital sites.

Our project information is now within a story board approach with regular updates provided to our Medication Optimisation Safety Committee. Our Chief Executive has pledged support to this national work. We are in regular contact with the Community Hospital Matrons to offer support, one of which has recently purchased magnetic pill timers for white board ward use, which we can keep to replicate.

#### **Outcome / Next Steps**

To date there has been a 13% reduction in medications prescribed out of the 30 minute window and three wards have achieved less than 10% of doses over 30 minutes.

We have recently liaised with our education department and mandatory training will be in place for all of our ward based staff going forwards to support this project.

Working with our acute trust, we are sharing valuable work and aiming to join up our project work.

We aim to extend the membership of our project group to incorporate service users and are applying for a small grant to obtain more magnetic timers for wards and to provide further education.

We eagerly await for results of the 2023 Community Hospital Association Innovation and Best Practice Awards for which we were recently shortlisted and understand we may have been successful !

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## **A multidisciplinary, comprehensive clinic for people with complex phase Parkinson's**

Lauren Evans, Louise Ebenezer, Fay Collier  
Princess of Wales Hospital, Bridgend, United Kingdom

### **Abstract**

#### Objectives

Complex phase Parkinson's represents a stage in the illness where the condition has significant impact on quality of life. This is could be due to motor fluctuations (including "off" periods and dyskinesia), non-motor symptoms, medication side effects or problems with memory and hallucinations. Assessing and managing these complex needs requires time and the expertise of a team of specialists. Our movement disorder team, based in a district general hospital in Bridgend, South Wales, consists of three clinicians (one Geriatrician with specialist interest in Parkinson's and two Parkinson's Nurse Specialists) along with connections to the wider multidisciplinary team, and cares for approximately 500 people with Parkinson's. We identified a need to provide timely and holistic care for patients with complex phase Parkinson's.

#### Interventions

We developed a multi-disciplinary, comprehensive clinic for people with complex phase Parkinson's. Patients identified to have complex needs are seen in "complex clinic" within 8 weeks. In a one-hour long clinic slot, the patient is assessed by the Parkinson's Nurse Specialist alongside a Geriatrician and a Physiotherapist. The collaborative approach and sharing of expertise allows us to best optimise motor function, address non-motor symptoms and assess memory. If appropriate, we discuss advanced care planning with the patient and family. We also address any co-existing medical problems that may interplay and perform bone health assessment. The clinic review may result in medication changes, implementation of non-oral therapies and referral to allied health professionals and/or social services. We address the burden of carer stress by referring to the appropriate setting; community services such as dementia care co-ordinators, social support and Age Concern to name but a few.

#### Outcome

In recent audit of 34 patients and their families seen in complex clinic, 92% of consultations took in excess of one hour to complete and create a clear plan in partnership with the patient, their families and the multi-disciplinary team. Seventy nine percent of patients continue to live in their own home and 35% of those have complex family dynamics. By building a rapport with these families as a unified team, we increase likelihood of acceptance of support from other services and awareness of what our team can provide. For motor fluctuations, 29% had referrals for non-oral therapies. There were 15 patients with a new diagnosis of dementia who had an ECG prior to commencing on a cholinesterase inhibitor within the same appointment

#### Next steps

Our team soon hope to add a permanent physiotherapist to attend our complex clinics following a successful trial of a staff member loaned from another team. We are also starting a dedicated dementia clinic in partnership with the mental health team specifically for our patients. There will be support from the third sector, such as dementia care. This clinic will also improve awareness of the complexities of Parkinson's dementia within the mental health setting.

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## **Final category: 1. Innovation in practice**

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### **Time Matters : It's Critical : How a group of NHS Professionals living with Parkinson's helped to put Parkinson's Medication onto the national agenda**

Jonny Acheson<sup>1</sup>, Clare Addison<sup>2</sup>

<sup>1</sup>NHS Parkinson's Professional Group, Leicester, United Kingdom. <sup>2</sup>NHS Parkinson's Professional Group, Redhill, United Kingdom

#### **Award categories**

1. Innovation in practice

#### **Abstract**

It is well documented that Parkinson's medication is delayed or missed regularly in healthcare settings. A lack of education means that it is not prioritised by hospital staff. A missed dose can lead to an increased risk of falls, an unsatisfactory physiotherapy outcome and an increased length of stay.

Currently only around 42% of people get their Parkinson's medications on time in hospital. In 2021-22, it was estimated that there were 45,945 excess bed days in England and Wales, one of the contributing factors being that people with Parkinson's had delays in their medication. In 2019 in Scotland, it was estimated that 100,000 doses of medication were delayed or missed.

In April 2022 a group of NHS Professionals living with Parkinson's embarked on a campaign to ensure that patients in hospitals across all 4 nations received their Parkinson's medications within 30mins of when they needed them.

The group identified that the long running Parkinson's UK 'Get It On Time' campaign needed to be renamed to emphasis the urgency of this in a healthcare setting. Their innovation was simply to call it 'Time Critical Medication' (TCM) as they knew NHS Professionals could identify with this.

They noted that previous work had just looked at the ward settings however they wanted to highlight and educate people that Time Critical Medication needs to be on everyone's agenda from the minute the patient accesses the NHS to when they are discharged.

To address the new name and to educate staff at the same time their second innovation was to record a 3 min video called Time Matter's : It's Time Critical. This was launched on social media on 11th April 2022

<https://vimeo.com/696514057>

The group then strategically composed a letter which was emailed personally to every Chief Executive Officer (CEO) of an acute hospital in England and every CEO of the health regions and boards in Scotland, Wales and Northern Ireland. The Chief Nursing Officers of all 4 nations were also emailed as well as the NHS Medical Director for England and the chair of the Association of Ambulance Chief Executives. They were simply asked to pledge their support to this campaign via email. This was then followed up by the Parkinson's UK local

campaign officers in England and the service improvement managers in Scotland, Wales and Northern Ireland.

One year of campaigning has resulted in over 100 pledges of support from Chief Executives of acute healthcare trusts, regional ambulance services, the Chief Nursing Officers and other NHS executives across all 4 nations.



## 6

# Parkinson's Passport Tailored for Patients

Peter Scholes

Isle of Wight NHS Trust, Newport, United Kingdom

### Award categories

1. Innovation in practice

### Abstract

**Objectives:** For patients to be given their medication on time when admitted to Hospital.

**Intervention:** Patients with Parkinson's Disease on the island expressed that they often struggled to get their medication on time, or at the right dose when admitted to Hospital. This resulted in relatives of these patient's often ringing the Parkinson's Nurse asking for intervention. With this in mind a co-productive approach was used and I began working on developing a Passport for patients to bring into hospital to help improve the understanding and adherence to time sensitive medication, as well as giving the Nurses a little information about the patient, especially in the "All about me" section, on how they are when they have their medication on time, including what they are able to do themselves, as well as a section to explain what happens to them if they don't get their medication on time. Discussion were held at our local Parkinson's coffee morning with patients about their fears, concerns, and for their thoughts on a Passport, that they would bring into hospital with them.

A discussion was had with other local and national trusts, who thought it was a great idea, as most of them had nothing tailored to their own trusts. I also spoke to the acute wards within the hospital to gain their thoughts on the passport. 30 Patients with Parkinson's were approached for their input and feedback, and if they would find it useful to have something to bring into hospital with them. A conversation with our pharmacy department also meant that they were on board the idea, and especially around the patient's managing their own medication when on the ward, and they provided me with the current Policy around patients self medicating, and it especially identified Parkinson medication and the importance of getting it on time. Our local Parkinson's UK group were also involved in the discussions. The Passport itself is on an A5 document with information about how to contact the Parkinson Service, as well as some guidance around how Parkinson's may affect the patient on admission. The Passport promotes giving patients time to respond to requests from the nursing staff or Dr's on the ward.

**Outcomes and Next Steps:** One of the main outcomes of the project was the passport being recognised by both the Community services as well as the Acute services within the trust. In order for this to be achieved I presented to both services and the Document steering group. They all agreed that the passport was a brilliant idea and that they cant wait to see it in practice. My next step is to present to all the ward managers within the trust, and give them a copy of the finalised Passport, so they can be shown to the ward staff, and they can familiarise themselves with it. This will also give them the opportunity to ask myself any questions they may have. It will also act as a learning tool for student Nurses.

## **The Role of a High Intensity Exercise Class for People in the Early Stages of Parkinson's within an NHS Outpatient Setting**

Amelia Khan

Guys and St Thomas' NHS Foundation Trust, London, United Kingdom

### **Award categories**

1. Innovation in practice

### **Abstract**

Parkinson's is a progressive neurological condition that is caused by a lack of dopamine within the Basal Ganglia. It is the fastest growing neurological condition in the world, affecting 145,000 people in the UK. Physiotherapy is a well-known and NICE recommended treatment for Parkinson's (NICE, 2017) and is advocated at all stages of the disease. The National Parkinson's UK audit (2019) found that physiotherapy intervention mainly consisted of exercise recommendations to people with Parkinson's (95.6%).

Within the field of Parkinson's, there is currently great focus on the impact of early intensive exercise intervention. Some studies have shown that early intensive rehabilitation can reduce the speed of deterioration and delay the need for increasing drug treatment (Frazzitta et al, 2018). A more recent study showed at 45 minutes of high intensity static cycling for three days a week (over a 6 month period) demonstrated positive neuro-plastic changes within the basal ganglia, these changes were also shown in improved objective and subjective markers (Johansson et al, 2021).

However all researched interventions require high dosage levels of physiotherapy which cannot be replicated with a NHS setting. There is currently no research which reviews the effect of a lower level of physiotherapy dosage within the early stages of Parkinson's.

We proposed a six week high intensity exercise class which comprised of 45 minutes of exercise (aerobic, strength, balance and stretching exercises) and a 15 minute informal education session. Participants had their balance, walking, quality of life and muscle endurance assessed pre and post intervention; outcome measures used were mini-BESTest, Parkinson's Disease Questionnaire- 39 (PDQ-39) and 60 second sit to stand test. Two cohorts, of 14 participants in total, engaged within the intervention. All participants improved in their outcome measures post intervention. All patients provided positive feedback post intervention and wished they had engaged with this intervention earlier on in their Parkinson's journey

Due to the nature of this intervention and funding we were unable to assess long term exercise habits or change within this cohort. This is an area we would like to address in a later project

# 11

## **Collaborative working to improve long-term exercise adherence in people with Parkinson's**

Jane Nyland

Tameside and Glossop Integrated Care NHS Foundation Trust, Ashton-under-Lyne, United Kingdom

### **Award categories**

1. Innovation in practice

### **Abstract**

#### **Collaborative working to improve long-term exercise adherence in people with Parkinson's**

Jane Nyland, Specialist Physiotherapist, Community Neurorehabilitation Team (CNRT)

Tameside and Glossop Integrated Care NHS Foundation Trust, United Kingdom

#### Objective:

To improve long-term exercise adherence in people with early Parkinson's by collaborative working with community exercise provider.

#### Intervention:

Since 2019, I have run a 'Power-Up-Parkinson's (PUP) group on behalf of CNRT, each being twice-weekly for 8-weeks. Based on PD Warrior, it is an exercise program, specifically designed to target the impairments present in Parkinson's and to slow its decline [1].

Most participants improve on balance, walking speed, stride length, dexterity and quality of life. Repeatedly, feedback was that participants wanted group to continue. I realised more support was needed to transition from exercising with CNRT to in the community. Working with people and communities is critical if we are to create a health and care service which offers personalised care [2].

In 2022, I met with Parkinson's UK and Active Tameside (council gym provider). A successful application was made for a Physical Activity Grant. This funded room hire to run CNRT PUP classes at council gyms, gym staff training in Parkinson's and for exercise equipment. Funding also covered sending information to update previous PUP participants on actions.

In the final week of each group, Active Tameside staff attended to discuss their exercise on prescription service and take referrals. Referrals were dealt with immediately to avoid a break in exercising.

#### Outcomes and next steps:

Through running PUP at Active Tameside gyms, our patients became familiar with location and staff. This has allowed a seamless transition onto the exercise on prescription scheme and long-term exercise. We have seen an increased uptake of referrals to Live Active as a result.

All the Gym Instructors, involved in exercise on prescription, have participated in PUP classes and done online training through Parkinson's UK website. They are more aware of Parkinson's and how to adapt exercise to benefit this client group.

The success of this project has been shared Trust wide, with the Greater Manchester Neurorehabilitation & Integrated Stroke Deliver Network and North West Parkinson's Nurses.

The next steps include a further application for funding from Parkinson's UK to extend this project. Also, initial steps have been made to establish better links with Glossop Leisure Centre, the other area that our team covers.

#### References:

[1] PD Warrior. PD Warrior [online]; 2023. [accessed 4 June 2023]. Available from: <https://pdwarrior.com/>

[2] NHS England. Working in partnership with people and communities: statutory guidance [online]; 2022. [accessed 4 June 2023]. Available from: <https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>

## 13

# Reducing #TimeCritical Medication Errors in a Major Trauma Centre

Robert Davies, Pearson Emma, Kevin Triscott  
University Hospitals Plymouth NHS Trust, Plymouth, United Kingdom

### Award categories

1. Innovation in practice

### Abstract

**Objective:** The aim of the initiative is to improve the in-hospital experience of People with Parkinson's (PwP) by reducing the incidences of harm experienced secondary to the impact of medication errors in the acute setting, including increased length of stay and reduced independence. Using established campaigns from Parkinson's UK (2022,) including 'Get It On Time' and '#TimeCritical', as a basis we have introduced a range of interventions, in a 'Swiss Cheese model', in a bid to mitigate potential hazards and reduce potential for error, and subsequent harm.

**Intervention:** Over the course of the pandemic our team started to introduce interventions to help improve medication safety. This started with carrying out medication audits to identify issues on the wards, provision of Parkinson's UK Blue Washbags to patients on the award winning New Patient Pathway and the introduction of Repeat Admission Patient Alerts (RAPA).

With the increased adoption of electronic systems including e-prescribing, there was increased capacity to further develop the scope of the interventions. This has included the introduction of electronic alerts that highlight that a patient is on #TimeCritical medication from the moment they are clerked into any Trust clinic or department, be it a planned or emergency admission.

This is supported by an online referral system, which includes prompts to tackle common problems including swallow and bowel issues, prompts to ensure accurate medication reconciliation<sup>1</sup> as well as a hyperlink to the OPTIMAL calculator to ensure the MDT is consistently using the same conversion tool to inform clinical practice.

Additionally, the team has worked extensively with the Specialist Pharmacist for Health Care of the Elderly to ensure that there is appropriate stock of Parkinson's medications throughout the wider hospital, including establishing a supply in the 'Night cupboard' and the creation of user-friendly lists to facilitate ward staff to find the nearest supply in the event they lack the medication on their own ward.

This has further been supported through the creation of Ward Resource packs and the development of staff information boards, as well as on-going expansion of the existing trust website to include information for both People with Parkinson's and their families, and also Health and Social Care workers, both within and external to our trust. Furthermore, we continue to run extensive training for staff, across all professions, grades and departments to raise awareness of Parkinson's, and associated conditions, and empower staff to provide high quality care for their patients.

**Outcome and next steps:** As a result of the interventions we have implemented we have found that the rate of Parkinson's medication prescribing and administration errors has reduced, with staff taking more proactive steps to ensure PwP get the right medication at the right time, and seeking timely assistance from our team when there is doubt or concerns about the impact of making changes to established regimes.

**References:**

Fitzgerald, R. Medication errors: the importance of an accurate drug history. *British Journal of Clinical Pharmacology*. Vol 67; 6: p671-675

## 'Getting it on time' at University Hospitals of Leicester NHS Trust

Hannah Flint, Elizabeth McKechnie

University hospitals of Leicester NHS Trust, Leicester, United Kingdom

### Award categories

1. Innovation in practice

### Abstract

Objectives:

Our project was to look at ensuring patients admitted to the hospital with Parkinson's received their medicines in a timely manner.

Intervention:

We set up a Parkinson's working group made up of pharmacists, nurses and a doctor from across the hospital to try and generate ideas. The ideas are about how we could improve and raise the profile of Parkinson's and how important it is to receive medicines on time. These meetings generated various ideas which we have taken forward.

Outcomes and next steps:

We have introduced various initiatives around improving understanding on Parkinson's and the medicines taken. The following is a list of those successfully completed:

- A short training video on medicines for Parkinson's called 'It's time critical'. This has been introduced and made mandatory training for all nursing, medical and pharmacy staff. Currently 56% of staff have watched the video.
- We have introduced a Parkinson's medicines emergency cupboard available on all 3 hospital sites. This is so that when the pharmacy department is closed nursing staff can get access to Parkinson's medicines if they haven't got it available on their ward. The aim is that no medicine dose should be missed because they couldn't get them easily. A poster has been sent to staff informing them how to get into the cupboards and a list of all the medicines which are kept in them.
- We have added an alert to our electronic patient system so that all patients admitted with Parkinson's can easily be identified. Staff on the wards will be able to recognise patients and know that they may need medicines at set times. From this alert we have been able to create what is called a 'SMART' list. This is a list of all current in-patients on the wards for the specialist Parkinson consultants to be able to review and offer support or advice when needed.
- We have improved our self administration of medicines scheme so that is easier for staff to use. We are actively encouraging ward staff to look at offer this as an option when patients are able and would like to do this.
- We have introduced a new way of measuring how we are getting on and if we are improving. We now measure the percentage of Parkinson's medicines which are given within 30minutes of the time that it was due on the prescription chart. We continue to measure the number of Parkinson's medicines which are not given because the nurse could not find them. The number being missed is small.

Our next steps are to take out 'Get it on time' resources to the medical wards with further teaching sessions to the staff. We will try different approaches to see which is the best method for improving our performance, for example notices above beds or use of alarm clocks.



## **Power UP! An exercise and education programme for people recently diagnosed with Parkinson's and their supporters.**

Suzanne Seymour

Royal Devon University Healthcare NHS Foundation Trust, Barnstaple, United Kingdom

### **Award categories**

1. Innovation in practice

### **Abstract**

Within my Physiotherapy clinic I was meeting people recently diagnosed with Parkinson's who needed an introduction to exercise to build their confidence to become active again. They also had a lot of similar question around their diagnosis, prognosis and were asking about meeting others in a similar situation. North Devon is rural and people can feel isolated. There is currently no programme for recently diagnosed people for me to signpost them to so I listened to what they required and designed a course for them.

Power UP! is an 11 week programme of exercise which introduces them to a range of exercise styles to help their Parkinson's symptoms. Whilst they are exercising the supporters have an opportunity to meet together in a relaxed cafe environment, with representatives from the local Parkinson's UK branch. The education sessions are delivered to everyone in the cafe. Topics discussed are those relevant to people recently diagnosed. Other professionals are involved (for example Speech and language therapy) as well as a talk given by someone living well with Parkinson's. The group has a maximum of ten people (up to 20 with the supporters) and is held in a local sixth form college.

My main aim of Power UP! is to empower people by;

- helping them understanding their symptoms
- knowing where to look for reliable answers
- when to ask for help (recognising signs and symptoms of change)
- creating a support network of friends
- connecting with the local branch of Parkinson's UK
- to become physically stronger and fitter to live well with Parkinson's
- finding exercise/activities they enjoy and would like to engage with

First Power UP! group started in September 2022 and has evolved over the year with three groups of people completing the course. Every participant has reported to have benefited in some way from attending. only 1 person did not complete the course and that was due to grandparent childcare duties. Two groups have set up a WhatsApp group. Most have joined the local Parkinson's UK branch with some stepping forward for roles within the branch. Subjective (EQ-5D-5L which measures health perception) and objective (6 minute walk test, Mini BESTest and 5 times sit to stand) measures are taken before and after attending. All attendees improved at least two of these outcomes. All participants after completing the course have signed up to local exercise classes and are maintaining them. Using the feedback from participants I plan to keep adding to and evolving the sessions. September's course will be 12 weeks so that I can include a Nordic walking exercise session and a talk by the dietitians.

## Final category: 2 Sharing learning and education

### 4

## Integrating Sialorrhoea (excess saliva) management into Parkinson's Services

Jyothi Adenwalla<sup>1</sup>, Biju Mohamed<sup>2</sup>, Constantina Marquis<sup>3</sup>, Ruth Lewis-Morton<sup>2</sup>, Mehrnaz Zadeh<sup>4</sup>, Chris Thomas<sup>2</sup>

<sup>1</sup>University hospital of Wales, Cardiff, United Kingdom. <sup>2</sup>University Hospital of Wales, Cardiff, United Kingdom. <sup>3</sup>university hospital of wales, Cardiff, United Kingdom. <sup>4</sup>university hospital of Wales, Cardiff, United Kingdom

### Abstract

#### Objective:

Physical and psychological consequences of sialorrhoea (drooling), a distressing symptom of Parkinson's, leads to a reduction in the quality of life for people with Parkinson's (PWP). This often under-recognised and under-treated problem significantly increases carer burden. Traditional treatments carry risks of systemic anticholinergic side effects, especially in the elderly. Botulinum neurotoxin A injection (BoNT A) has recently been approved by NICE.

#### Intervention:

Our team established a dedicated clinic within the Parkinson's service to offer BoNT A injections. The clinic was facilitated by the clinic nurse, co-ordinator and healthcare support worker.

Our first clinic was held in June 2021. We based eligibility criteria on scores from the Drooling Severity and Frequency Scale (DSFS) questionnaire with scores 6 or more being offered treatment. Our initial practice was to administer 50 units of BoNT A to new patients with follow-up patients getting full recommended 100 units at 4 months intervals.

Our clinic nurse contacted patients before and after the injection to explain the process, clarify queries and collect pre and post injection scores using the DSFS and EQ-5D quality of life (QoL) questionnaires. A bespoke information leaflet was also prepared.

#### Outcomes:

We reviewed data collected between June 2021 and June 2022. We performed a total of 42 interventions in 28 patients (average age 76 years, average clinical frailty score 6). With 50 units of BoNT A, 33% of patients found improvement confirmed by DSFS and 28% improvement in QoL in contrast to a 75% improvement on DSFS and 35% in QoL with 100 units. No significant side effects were reported. Treatment with BoNT A seems to be safe and effective in our frail, elderly cohort of patients.

Psychology colleagues assessed psychosocial impact of the BoNT A injection including measures of quality of life, self-esteem and self-compassion in a small group of PWP (n=6).

They compared psychometric measures before and two weeks after treatment and completed semi-structured interviews post treatment. They observed improvements in self-esteem and social integration.

#### Future Steps:

We reflected on the data and learning made in clinic. We now offer the full recommended dose for all patients based on study recommendations and our clinical experience. We continue to audit data for 2022-23 to review our ongoing practice with further refinement of the role of the clinic nurse who is pivotal to the smooth-running of the clinic. In future, we aim to support colleagues hoping to gain expertise in BoNT injections for sialorrhoea and continue to present our service model in national meetings to share good practice.

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## 7

### Improving how we talk about Parkinson's dementia

Rimona Weil<sup>1</sup>, Joanne Thomas<sup>1</sup>, Anne Marr<sup>2</sup>, Ruairadh O'Connell<sup>3</sup>, Cassie Hugill<sup>1</sup>, Moïse Roche<sup>1</sup>, Ivelina Dobрева<sup>1</sup>, Charlotte Dore<sup>1</sup>, Sian Rose<sup>1</sup>, Janet Roberts<sup>4</sup>, Sion Baldwin-Jones<sup>5</sup>  
<sup>1</sup>University College London, London, United Kingdom. <sup>2</sup>Central Saint Martins, London, United Kingdom. <sup>3</sup>Independent artist, London, United Kingdom. <sup>4</sup>Person with lived experience, London, United Kingdom. <sup>5</sup>Parkinson's UK, London, United Kingdom

#### Abstract

Objectives:

Dementia is common in people with Parkinson's (six times more likely than in the general population<sup>1</sup>). However, those working with the Parkinson's community avoid discussions about it due to lack of training and worries about negative reactions from people with Parkinson's. 86% of healthcare professionals said they don't have the training to provide high-quality care for people with Parkinson's dementia<sup>2</sup>. People with Parkinson's find it hard to talk about dementia, due to the taboo of dementia and lack of support and guidance for themselves and carers<sup>2</sup>.

However, having conversations about Parkinson's dementia means that people with Parkinson's can participate in research, and access appropriate treatment and support.

Our objectives were to:

- Identify the roots of discomfort linked with dementia in the Parkinson's community through creative workshops
- Use outputs from these workshops to co-produce a pair of booklets for people with Parkinson's and healthcare professionals to improve conversations about Parkinson's dementia and access to support
- Provide healthcare professionals with clinical tools to diagnose and manage Parkinson's dementia and associated symptoms
- Ensure our resources are relevant to underrepresented groups, especially the Black African community which is often under-represented in Parkinson's research and communication

Intervention:

We worked with artists at Central Saint Martins and people with Parkinson's to deliver a series of creative workshops for people with Parkinson's and their families. The workshops explored the taboo of dementia in Parkinson's and how people with Parkinson's want to talk about dementia in a clinical setting.

We used outputs from the workshops to co-produce a pair of booklets to improve these conversations in the clinic. People with Parkinson's, family members, and Parkinson's experts from around the UK took part in focus groups to co-create the booklets. We had input from a range of geographical and clinical settings, based on the highest quality clinical evidence.

We ensured the voices of people affected by Parkinson's were at the heart of this work. We involved people with lived experience of Parkinson's at every stage from planning the project, to involvement in the workshops, to co-designing and improving the toolkits. A team member whose research explores dementia within Black and Minority Ethnic populations ensured the project and resulting booklets were inclusive and accessible to underrepresented groups.

#### Outcome and next steps:

We have co-produced a pair of booklets to improve conversations about Parkinson's dementia. One is designed for people living with Parkinson's and their families. The other is for healthcare professionals, providing guidance on how to diagnose and treat Parkinson's dementia. Our booklets have been adopted by Parkinson's UK as resources to support people with thinking and memory problems in Parkinson's. This will mean they have wide reach for people worried about these symptoms.

#### References

1. Aarsland. Risk of dementia in Parkinson's. Neurology 2001
2. "Nobody really knows us" The state of health and social care for Parkinson's-related dementia. Carney 2021

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## **'Connect and Conquer'- A Health, Community and Charity embedded partnership programme to increase exercise and physical activity provision for people living with Parkinson's.**

Sophia Hulbert<sup>1</sup>, Rob Harrison<sup>2</sup>

<sup>1</sup>Cornwall Partnership NHS Foundation Trust, Bodmin, United Kingdom. <sup>2</sup>Active Cornwall, Truro, United Kingdom

### **Abstract**

#### Objective:

Cornwall Partnership NHS Foundation Trust is fortunate to have a dedicated Parkinson's Physiotherapy service. We are passionate about promoting and supporting physical activity and exercise for people living with Parkinson's (PwP). This not only allows us to deliver best practice within our healthcare service but strives to help our Parkinson's community to establish active lifestyles.

Through focus groups and workshops, PwP told us the best way to cater for their needs would be for activities to take place in the community and outside of the health sector.

#### Intervention:

In 2019 we started working with Active Cornwall to promote greater choice, autonomy, and flexibility to the types of activities available for PwP in the community. 'Active Cornwall' hosted by Cornwall Council, part of the Active Partnership Network and funded by Sport England, work together to tackle inequalities by transforming lives and communities through Physical Activity & Movement.

We recognised resources were limited so devised a free online training package offered to all activity and exercise providers in the county. The training includes 6 mini-modules designed to increase awareness of Parkinson's; understand the condition and symptoms; learn how best to support PwP in a range of activities; and the importance of being highly active for PwP. Jane Rideout, a highly active member of the Parkinson's community and avid promoter of the role of exercise in the management of her Parkinson's provides an essential insight into 'living with Parkinson's' and how 'exercise changed her life'.

#### Outcomes and next steps:

Following completion of the training, activity providers are invited to enrol on a database. This is shared with the community as a resource list of 'Parkinson's friendly activity providers'. In addition, partnership with local Parkinson's UK hubs allows us to offer up to 50% reduction in the cost of the activities for the first 12 sessions. This is a fantastic incentive for PwP to try new things, make new friends and hopefully embed the activity into their regular exercise routine. We are delighted to have trained over 50 providers now ranging from yoga, walking, surfing, dance, swimming, boxing, aerobics, climbing and many more.

We have now taken this training further, running the first ever 'Connect & Conquer Event' bringing the trained providers and PwP together in a local leisure centre to demonstrate mini taster sessions, meet each other and build peer support within local communities. The first event was a great success, with the second planned for July 2023 and the ambition for this to be a twice-yearly event.

The partnership between the NHS trust and Active Cornwall has enabled us to grow a high quality, evidenced based and sustainable approach to continual training of new 'Parkinson's friendly providers'. It has also built greater awareness of the condition and importance of exercise within the exercise community. Most importantly it has provided choice, opportunity, and access to a range of activities for PwP to self manage their condition in a highly active and enjoyable way.

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## **Co-designed Parkinson's Awareness Podcast for Undergraduate Student Nurses in Northern Ireland.**

Sophie Crooks, Gary Mitchell, Gillian Carter, Christine Brown Wilson, Patrick Stark, Shannon Copeland, Susan Carlisle, Amy Wong, Johanna McMullan, David Blake, Elaine Lyons  
Queen's University Belfast, Belfast, United Kingdom

### **Abstract**

#### **Objective**

Educating nursing students is particularly important to ensure they are provided with resources to enable them to see the entire clinical picture as a whole and are prepared for clinical practice. Recent evidence has highlighted that Parkinson's education for nursing students is often limited. In recognition of this gap in our nursing education, I was part of a team that co-developed a podcast about the disease. Our main aim was to raise awareness and disseminate knowledge about Parkinson's to year one undergraduate nursing students and to give a voice to people with Parkinson's, as well as their caregivers and nurse specialists.

#### **Intervention**

The team consisted of more than twenty people including people living with Parkinson's, carers and volunteers for those with Parkinson's, Parkinson's nurse specialists, nursing students, charity representatives from Parkinson's Disease UK and nurse lecturers from QUB. The team worked to co-design a 75-minute audio podcast about Parkinson's. It was comprised of three main segments where nursing students hosted interviews with a person living with Parkinson's, a carer for someone with Parkinson's and a Parkinson's specialist nurse. Year one nursing students were given access to the Parkinson's podcast for 30 days. Participation in the podcast was a mandatory part of the year one programme. Students were permitted to listen to the podcast at any convenient time within this 30-day period.

#### **Outcomes and Next Steps**

We asked students to complete questionnaires before and after listening to the podcast to see how their knowledge changed after listening to the podcast. Findings confirmed a significant increase in knowledge of Parkinson's post-podcast with students scoring an average of 52% before listening and 85% after listening. In addition to this, we also ran focus groups with students who had listened to the podcast. Throughout these focus groups, students discussed finding the podcast beneficial for applying knowledge gained from the podcast to their experiences in healthcare. In particular, students found it valuable for fostering empathy about living with Parkinson's and recognising things they could do in practice to improve care (for example, being patient, using a slower pace).

In the future we hope to make this podcast available to a wider audience with the aim to disseminate Parkinson's knowledge and awareness. I have been so inspired by the impact of this work, that I have had the opportunity to take the lead in writing-up the evaluation of this project for an academic journal. I have also been successful in gaining an all-Ireland PhD scholarship to continue working in the field of Parkinson's Disease at Queen's University Belfast which I hope will make a difference to those living with Parkinson's across the globe.



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## Developing capacity to provide sustainable physical activity opportunities for people with Parkinson's

Julie Jones<sup>1</sup>, Aimi McGeough<sup>2</sup>

<sup>1</sup>Robert Gordon University, Aberdeen, United Kingdom. <sup>2</sup>NHS Tayside, Perth, United Kingdom

### Abstract

Current research highlights the value of exercise for people with Parkinson's (PwP's). The benefits of exercise extend beyond physical benefits, with research highlighting social benefits as well as benefits to health and well-being. Despite the wealth of research recommending exercise many PwP's are inactive. Lack of access to exercise opportunities and staff who are knowledgeable about Parkinson's have been reported by the Parkinson's community as key factors limiting exercise participation.

Physiotherapists are well placed to prescribe exercise for PwP's. However, few PwP's have access to specialist physiotherapy, and for those who do receive physiotherapy, this is often time limited. Inadequate access and short-term service provision highlights the need for a different approach to ensure PwP have access to long-term exercise opportunities.

Delivery of exercise within local community centres provides a more sustainable model of supporting long-term exercise for PwP's. Providing exercise within community settings also reduces commonly cited barriers to exercise. However, the majority of fitness instructors have no training or experience of working with older people or those with complex needs such as PwP's. Educational resources are available via the Parkinson UK learning pathway. However these educational resources does not address how to adapt exercise prescription for PwP's or provide guidance on the key considerations when setting up and delivering exercise classes to meet the needs of PwP's.

To address this need and to enable Exercise Professionals to be both knowledgeable and appropriately trained to delivery exercise classes for PwP's we have developed a six-hour research informed interactive and practically based educational programme. Training combines theoretical principles and practical groupwork and tasks. The content of the programme is specifically mapped to the Chartered Institute for the Management of Sport and Physical Activity standards. The key objectives of the programme are to:

- demonstrate an understanding of Parkinson's.
- identify the key Parkinson's symptoms and discuss how these impact movement and function among PwP.
- Identify key Parkinson's medications and the impact these have on exercise prescription.
- demonstrate an understanding of the benefits and types of exercise for PwP.
- demonstrate an ability to design and develop effective exercise programmes for PwP
- discuss key considerations for setting up and delivering exercise classes for PwP

To date 55 Fitness Instructor have completed the training. Due to Covid-19 initial training was delivered online, with recent training being delivered face-to-face allowing a greater proportion of the training to be practically orientated. As a result of the training 28 classes have been set up throughout Scotland including the Borders, Aberdeen, Aberdeenshire, Perth, North Ayrshire, North Lanarkshire, East Renfrewshire, East Lothian, Edinburgh, and Fife. Evaluation of training indicate that participants were highly satisfied with training. All attendees reported feeling prepared and confident to deliver exercise classes for PwP following engagement in the training. Future developments include:

- Delivery of further training.
- Gain industry recognised accreditation for training
- To formalise post-training support network for support fitness instructors long term learning requirements long

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# Final category: 2. Sharing learning and education

18

## Educating a Multi-Professional Workforce

Robert Davies, Emma Pearson, Kevin Triscott  
University Hospitals Plymouth NHS Trust, Plymouth, United Kingdom

### Award categories

2. Sharing learning and education

### Abstract

**Objective:** As a multi-disciplinary team we identified the need for an evolving education programme that addresses the needs of People with Parkinson's (PwP), reflects the current evidence base and is delivered flexibly to maximise engagement. As an acute NHS Trust we have high staff throughflow, therefore interventions must be repeatable, accurate and sustainable.

**Intervention:** To educate, inform and support the workforce about Parkinson's, its symptoms and its management we have produced training materials, with information to cater for different audiences. This has included teaching both within our trust, and more widely in the local Universities.

Education is delivered via face-to-face presentations, online webinars and one-to-one shadowing opportunities, open to all clinical staff not only within our Trust, but also to newly developing Parkinson's teams throughout the South West and beyond. Using presentations, leaflets, posters and both printed and electronic media we have broadened the reach of our offer to a wider audience. This has included developing ward resource packs, creating an in-hospital Parkinson's notice board and broadening the content on our public, external facing website.

Delivery is tailored to the group to whom we are presenting, which has included staff of all grades and professions. This tailored approach enables us to ensure key messages, e.g., the Get It On Time and #TimeCritical campaigns are highlighted in a way that has more meaning and emphasises the impact on the PwP. In the context of delivering training to International Nurses, Nurse Associates and Medical Doctors this has meant discussing the pharmacology of the medications to help them better understand why they are prescribed at specific times and highlighting the risks of late/ missed doses and the subsequent impact on PwP. For Physiotherapists, Occupational Therapists and Healthcare Assistants we explain how medication impacts physical and psychological symptoms and how this can impact on the ability to engage care and rehabilitation. Similarly, we deliver training to Physiotherapy and Nursing students, through the local universities, to promote early awareness of Parkinson's amongst our future workforce. By engaging with students, we are able to get them enthusiastic about caring for PwP and they are more likely to act as ambassadors for PwP when out in clinical practice and help improve the culture of learning<sup>1</sup>.

**Outcome and next steps:** Engagement with the Parkinson's Specialist Team has improved, staff have a clearer understanding of the challenges PwP face and how these might be overcome. The information being provided on referrals is more detailed and staff are taking remedial action whilst the PwP is waiting for review, helping to reduce rates of deconditioning and loss of independence, positively impacting on reducing length of stay.

One of our next steps is to ensure the principles of the Parkinson's Excellence Network '10 Recommendations of Time Critical Medication' are incorporated within our teaching, thus encouraging best practice and practical support within all wards and departments.

**References:** 1. Stevenson, R. and Moore, D. A Culture of Learning for the NHS Journal of European CME. Vol 8: 1

## **A Quality Improvement Project to incorporate routine Bone Health assessment into a Parkinson's Clinic**

Anoushka Kitson<sup>1</sup>, Hanaa Ali<sup>1</sup>, Sarah Page<sup>2</sup>, Biju Mohamed<sup>2</sup>

<sup>1</sup>Cardiff University, Cardiff, United Kingdom. <sup>2</sup>Cardiff and Vale UHB, Cardiff, United Kingdom

### **Award categories**

2. Sharing learning and education

### **Abstract**

**Objectives:** People with Parkinson's (PWP) are at a greater risk of fractures compared to the general population (1). The cause of this is multifactorial and creates an added complication for PWP, impacting overall health, morbidity, and quality of life (1). Furthermore, the assessment of Bone Health in Parkinson's clinics was deemed a priority area, following data from the 2019 UK Parkinson's Audit (2), encouraging new service improvement models. Our project focuses on improving bone health assessment in PWP, by integrating and trialling different models of assessment in our clinics. We believe that this implementation, alongside routine practise, will focus on delivering better care and support, enabling the best outcomes and standards of care for PWP.

**Intervention:** Our project was a 12-week medical student led project, supported by the specialist Parkinson's team. To establish a baseline of current practice, a retrospective fracture risk assessment was carried out for 141 patients who attended the Parkinson's clinic in the previous weeks, under the Cardiff and Vale Health Board. This was achieved by analysing clinic lists and retrospectively applying the Bone Park algorithm to this cohort to identify unmet needs, missed opportunities but also areas of good practice. The Bone Park algorithm is a systematic approach to assess the fracture risk in PWP (1). Our focus group then developed a Bone Health proforma, which would be used routinely to screen the bone health of PWP. The views and opinions of our patients are central to the design and implementation of the proforma. With the involvement of our multidisciplinary team, we then trialled the best method of routinely using this proforma in our clinic - clinician led, patient led, or healthcare assistant led.

**Outcomes:** The retrospective analysis showed that 61.7% (n=87/141) of the 141 patients required bone health intervention. Out of the 141 patients, 41.4% of patients required initiation of vitamin D supplementation. 40.2% of patients required a DEXA scan, to measure their bone density. 18.4% of patients required initiation of bone strengthening treatment. The outcomes of our project provided compelling evidence, that routine bone health should be better integrated into Parkinson's management.

Our interim analysis of implementing the bone health proforma reveals that clinician led administration would be the best model as patients needed support filling the proforma and further clarity. Healthcare assistants needed support and training regarding medical terminologies. Patient preference, reduction of duplication and repetition, and improved accuracy indicate clinician led administration of the bone health proforma is the optimal way forward. We have also identified that the multi-disciplinary team need further training and education around bone health which we will incorporate. We aim to do this by incorporating this into our Parkinson's web app which we currently use for patient information and education.

## **Final category: 3 Person-centred approach**

**22**

### **The South Manchester Parkinson's Team - A comprehensive and integrated service from diagnosis through all stages of Parkinson's**

Lindsey Wileman, David Ahearn, Ailish Fountain, Zena Townson  
Manchester University NHS Foundation Trust, Wythenshawe, United Kingdom

#### **Abstract**

Our aim is to offer seamless and comprehensive Parkinson's care from diagnosis through all stages including the end of life with our multidisciplinary team and expertise. We achieve this through working with flexibility, removing traditional boundaries to care and being responsive to patients' needs.

Alongside the clinical aspects of care, we offer involvement in local and national research opportunities. We have a strong focus on teaching and sharing expertise, involving nursing, therapy and medical students and doctors in training, or holding education events for groups such as local GPs or palliative care specialists.

Our core team of two geriatricians and two Parkinson's specialist nurses work across the specialist Day Hospital outpatient clinic, the community and in hospital, as outlined below.

#### Day Hospital outpatient clinic:

Our long-established multidisciplinary Day Hospital clinic continues to grow and innovate with the aim to offer comprehensive service in a friendly, comfortable and patient-focused setting. It is run by geriatricians and Parkinson's specialist nurses alongside physiotherapy and occupational therapists, with close links to other allied health professionals and our partners in the community and voluntary sector. Through the clinic we cover the spectrum of Parkinson's care from diagnosis, management of complex symptoms, specialist falls service, preventative medicine (such as bone health assessments), and advance care planning opportunities. Additional clinics include a Parkinson's Kinetigraph (PKG) service, apomorphine initiation and a clinic dedicated to advanced Parkinson's with a focus on advance care planning. A telephone advice line with answerphone service means we are contactable at any time if questions or problems arise.

We work closely with our neurology colleagues and aim to provide a smooth transition of care for those patients who require a more multidisciplinary focus of management

Following patient feedback we have successfully initiated popular patient and team learning events – afternoon meetings with tea and cake, presentations, and Q&A with members of the MDT, attracting people with Parkinson's from neighbouring services too.

#### Community:

For those people with Parkinson's unable to attend the clinic setting we continue our care in the community with geriatrician-led home visits to homes or care homes or local psychiatry unit. Our community service is open to any local residents with Parkinson's who may have previously been under other services such as neurology or psychiatry teams.

Hospital:

Our team work across the acute hospital services, from the emergency department through to a dedicated medical ward with Parkinson's expertise and skills. We use the recently-developed electronic patient record to be alerted to patients who may be presenting in other areas including the critical care unit or surgery, providing specialist Parkinson's care in many inpatient settings.

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**Final category: 3. Person centred approach**

**15**

**Multiple initiatives for a personalised and person-centred approach for people with Parkinson's (PwP) in Lincolnshire**

Deborah Whitfield

Lincolnshire Community Health Services, Lincolnshire, United Kingdom

**Award categories**

3. Person centred approach

**Abstract**

The Lincolnshire Community Parkinson's team are passionately dedicated to improving services for PwP, whilst appreciating wider NHS system pressures and a limited financial envelope. We have worked on projects and initiatives to develop a patient-centred approach.

There has been an inequity of nursing service provision due to commissioning structures. Following project planning, all patients now come under the LCHS service, and if admitted Parkinson's Nurses support the inpatient stay and ensure a smoother transition back home with prompt communication to the community service. Setting up of alerts when a patient is admitted allows us to be more proactive in this approach. We now also accept different Parkinsonisms, so we can continue to support patients, even if their diagnosis changes, which is often the time they need most support and have already made strong connections with the team. Meetings have been established with the hospital Parkinson's Nurses to share experiences, work together on joint projects and support each other with clinical supervision. All this ultimately helps with patient experience.



Clinician-led paperwork changes have aided assessments. We now ask what is going well for the patient and celebrating self-management of their condition, rather than just concentrating on the issues. We are adopting a “what matters to you” initiative and supporting the patient to define patient-centred goals. The Physiotherapy discharge letter is now addressed to the patient, with the GP and consultant copied in, so the language is more patient focussed and highlights their self-management actions and celebrates their successes with therapy. Through the Patient Activation Measure (PAM) questionnaires we are understanding the patient activation level and their knowledge, skills and confidence to manage their health condition(s). As part of the PAM implementation, the team engaged in Motivational Interviewing training that has equipped us with different skills to have a better patient-centred conversation.

We offer follow-ups at intervals to meet patient need, activation level and stage of their condition. PwP’s can contact the service between planned reviews, to ensure that they get support that they require. The team attend Multi-Disciplinary meetings, often with patients and carers present, to ensure that their needs and wishes are clearly heard. We have complex pathways in Lincolnshire, so throughout 2022 held multiple stakeholder events with different professionals to understand how we can simplify and achieve better outcomes. This had led to dedicated referral routes into mental health services. Admin teams have close links to clinical staff and through training they have better appreciation of how to support people with Parkinson’s on the phone, allowing them more time to talk.

We strive to obtain patient feedback in the service; through the Friends and Family Test, the Parkinson’s UK audit (completed for the first time in 2022), and through a 15 steps programme (volunteers gathered patient experiences of the service) to listen to their voice. Through initialisation of a digital self-monitoring platform, we have collected expert patient feedback to aid development of question sets that are more user-friendly and achieve better outcomes.

## **Final category: 4 Community support**

### **5**

## **The Get Started Programme - It's more than just online exercise!**

Maria Lewis<sup>1</sup>, Sally Tawhai<sup>1</sup>, Anna Langridge<sup>2</sup>

<sup>1</sup>Reach Your Peak, Cardiff, United Kingdom. <sup>2</sup>1 FitLife, Bournemouth, United Kingdom

### **Abstract**

Reach Your Peak

An online exercise community for people with Parkinson’s in the UK founded by physiotherapists Maria Lewis & Sally Tawhai. Our programmes give our community knowledge, expert advice, Parkinson specific workouts and access to like-minded people with Parkinson’s. We empower people with Parkinson’s to become their own expert at exercising for their condition.

1FitLife

A leading creative agency for wellness, health & fitness content. We bring years of specialist experience from different industries; Rehabilitation, Wellness, Connected Fitness, Digital, TV & Music, combined to create the perfect health & wellbeing content. We understand how to produce content that creates a powerful connection with the audience.

## Objective

Our aim was to produce a 10-week online exercise programme for people with Parkinson's. To produce a programme that was engaging, fun, informative and inclusive. The important role exercise plays in the management of Parkinson's symptoms and its potential for disease modification is well understood but forming an exercise habit is challenging in this population. Having access to an exercise programme that is both engaging, and fun is important, (1).

## Intervention

There is emerging evidence on the benefits of exercising for Parkinson's. Exercising online gives people added benefits of exercising at a time that best suits them. Combining this with accountability and support which are also important factors will have a greater success in forming an exercise habit that will last a lifetime, (1).

Access to online exercise can benefit many people with Parkinson's, those with no local access to community exercise or those struggling to commit to set times. Our existing Reach Your Peak community were invaluable. Their insight and feedback informed the creation of the programme. The collaboration between Reach Your Peak and 1FitLife has allowed us to create an evidence-based exercise programme that engages the audience and is suitable for a wide range of people with Parkinson's.

Get Started is everything needed to exercise for Parkinson's. It's an online exercise programme, prescribed by expert physiotherapists, that gradually builds in intensity and duration over 10 weeks, reaching the recommended exercise dose for Parkinson's, (2). There is an exercise handbook which accompanies the programme, giving people the knowledge and skills to become their own expert. Also access to expert advice and a community of like-minded people exercising for their Parkinson's.

We are carrying out a service evaluation study to learn more about the demographics of people using the programme by measuring people's exercise knowledge, fatigue levels and strength pre and post programme, as well as their adherence to exercise.

## Outcome

The programme has received positive feedback from people on completion. The data will help us develop further exercise programmes and future opportunities for collaboration.

## References

1. Schootemeijer S, van der Kolk N, Ellis T, Mirelman A, Nieuwboer A, Nieuwhof F et al. Barriers and Motivators to Engage in Exercise for Persons with Parkinson's Disease. *Journal of Parkinson's Disease* [Internet]. 2020; 10(4):1293-1299.
2. Parkinsons Exercise Recommendations. Parkinsons Foundation. 2021 [2021 May 25].

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## Bigger & Better - fighting back against Parkinson's

Emma Bracher

Bigger & Better, Warwick, United Kingdom

### Abstract

**Objective:** As an Occupational Therapist, I am passionate about helping people to take a proactive role in their well-being, and I have long had a specialist interest in Parkinson's. When my Dad was diagnosed in 2016, I started to focus on how best to help people with self-management of their Parkinson's. At that time, there were few exercise opportunities in our area for active and newly diagnosed people, and nothing that focused on the high-intensity, high-frequency and high-amplitude elements that have shown to be the most effective for people with Parkinson's. My Dad did not want to join a seated exercise group and, as he was struggling to come to terms with diagnosis, was reluctant to meet other people with advanced Parkinson's symptoms. I started to think that there must be others out there feeling the same way, and Bigger & Better was born.

**Intervention:** Armed with knowledge from my LSVT Big and PD Warrior training, we set up our first class. Over the last 6 years, Bigger & Better has grown into an independent, therapist-led service that offers a range of exercises classes specifically for people with Parkinson's with mild to moderate symptoms.

We work alongside our local Parkinson's UK branches. We currently run 10 Parkinson's-specific classes a week, and provide support to over 80 people living with Parkinson's. Classes are run by experienced exercise coaches, who are trained and supervised by myself. We also have two Physiotherapists to support and advise our members.

We promote exercise as an essential component of condition management. We encourage high intensity and high frequency. We target the small and slow movement commonly experienced by people with Parkinson's, as well as balance and mobility impairments. We teach people to think differently about how they move and how to maintain 'bigger and better' movement. We use a functional exercise approach to help people maintain independence in their daily lives.

Our classes are fun, motivating and supportive. There are no judgements. Our coaches understand that people can feel different day by day and even hour by hour. We understand that some weeks people will want to work harder than other weeks, and we encourage people to turn up even if they don't feel up to exercising - sometimes just the social stimulation and peer support can work wonders.

**Outcomes and Next Steps:** As well as reporting improvements in general physical functioning, our members have reported that their confidence and mental health have improved, and that they find the classes a great source of peer support. Mixing with others helps them to realise that they are not alone. Some of our members had become quite isolated following diagnosis, and coming to our classes has got them active and socialising again. Members meet for coffee after class, and often arrange to meet up outside of our sessions. Great friendships have been formed - some of them life-changing.

We plan to continue growing, to help as many people as we possibly can.

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## **The Exercise Hub - A national education and peer support network for professionals, enhancing the community exercise experience for those with Parkinsons across the UK.**

Julie Jones<sup>1</sup>, Beccy Oliver<sup>2</sup>, Bhanu Ramaswamy<sup>3</sup>

<sup>1</sup>Robert Gordon University, Aberdeen, United Kingdom. <sup>2</sup>Thorpes Neuro Rehab, Eversley, United Kingdom. <sup>3</sup>Honorary Visiting Fellow, Sheffield Hallam University, Sheffield, United Kingdom

### **Abstract**

A substantive body of research exists supporting the value of physical activity for people with Parkinsons. Physical activity is thought to positively impact the motor and non-motor symptoms of Parkinsons as well as provide those living with Parkinsons a means to meet others, offering potential for shared experience. Current research highlights that people with Parkinson's value seeing professionals who understand the complexity of Parkinsons, which in turn promotes and motivates changes in physical activity behaviour. National guidelines also advocate that people with Parkinson's should see a Parkinson's specialist. However, the Parkinsons UK audit in 2017 highlighted that few people have access to specialist exercise professionals, which could be attributed to the lack of training available.

[The Exercise Hub](#) was established in 2015 by a small group of passionate physiotherapists in recognition of the lack of training and education available for professionals in this arena. The sole purpose then and now is to raise the profile and quality of exercise provision for people with Parkinson's within their local communities.

What the Exercise Hub has achieved:

1. Since 2015 the Exercise Hub has grown to over 500 members from all over the UK, providing education and training, as well as providing a peer network to support professional practice, mentorship and a platform to share best practice nationally. Using the online platform - Basecamp, members can share ideas, ask questions, seek advice and refer clients to other therapists. This informal safe space has brought people together, and provided a strong community feel across therapy/exercise professional divide.
2. Since 2019, the Exercise Hub has hosted monthly Zoominars covering a broad range of topics from experts within the field to ensure that members remain informed of the current best practice in turn informing their practice.
3. The Exercise Hub have delivered three study days attracted international speakers on a range of topic areas, bringing together the Exercise community. These have been a huge success in educating professionals but also fostering collaborations that have benefitted the wider Parkinsons community.
4. The core members of the Exercise Hub were instrumental in the development of the [Parkinsons UK Exercise Framework](#) -providing guidance for both people with Parkinsons and professionals on the optimal means of exercise prescription and implementation into practice. The development and implementation of the exercise framework has been presented nationally at Physiotherapy UK.
5. The core Exercise Hub members also provide a sounding board to the Parkinson's UK Physical Activity Team contributing to the recent Parkinsons Induction training and Being Active with Parkinson's guide. Through this consultancy role the Exercise Hub contribute and support the delivery Parkinsons UK Physical activity strategy.
6. The core Exercise Hub members have published in Practical Neurology and Advances in Clinical neuroscience and Rehabilitation highlighting the value of exercise to the

wider Multidisciplinary team and driving up standards for the Parkinsons community through our educational arm.

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# Final category: 4. Community support

1

## Positivity in the face of Adversity!

Adam Poulter

Foundations Physio, Farnham, United Kingdom

### Award categories

4. Community support

### Abstract

For the past 3 years Foundations Physio have been supporting our local Parkinson's branch (Guildford and Waverley) and it's members with the provision of subsidised exercise classes. Run by our excellent team of Amado Bola (Neuro Physio and Pocket Rocket) and Kate Poulter (Rehabilitation Assistant and fancy dress planner) we have supported a cohort of around 60 participants through COVID (running online classes and even creating our own YouTube channel) and championed the positive impacts of exercise on the condition.

Our classes, which are circuit based, often involve a combination of PD specific exercises, weight training, pilates and cardiovascular exercise. Through Amado and Kate's positive, enthusiastic and supportive approach most of our members have been continuously coming to our classes for the past 3 years and show no signs of slowing up!

## 14

# **Bounce Back Exercise: An inclusive exercise community for people with Parkinson's**

Beth Boxall

Bounce Back Exercise, Croxley Green, United Kingdom

### **Award categories**

4. Community support

### **Abstract**

In March 2020, I started Bounce Back Exercise to create more opportunity and support for people with Parkinson's to experience the benefits of exercise.

### **Objectives**

To establish weekly in-person and online exercise classes to help people with Parkinson's experience the physical and psychological benefits of exercise and promote lifelong engagement in physical activity.

### **Intervention**

In January 2022, I set up the first of our in-person Parkinson's Power exercise classes with the support from the West Herts branch of Parkinson's UK. This class takes place in a local studio in Croxley Green. The class involves a 15-minute warm-up followed by two rounds of 'Power' exercises, some balance challenges, and stretches to finish. I have also put on quarterly socials which take place at the end of the exercise class. This creates more opportunity for the group to get to know one another better. This includes our Christmas social and last year's Jubilee themed social!

In October 2022, I launched the second of our Power classes in Hertford thanks to funding from the Parkinson's UK Physical Activity Grants Programme.

In addition to our in-person classes, I also provide support through the Bounce Back Exercise Online Programme which consists of four weekly exercise classes delivered via zoom. Exercise classes are designed to address common disease symptoms including muscle weakness, balance, coordination, and mobility. Our functional exercise classes aim to replicate movements done in day-to-day life e.g., climbing stairs, stacking shelves, sitting to standing, picking up shopping. I also host online socials, quarterly workshops, and monthly challenges to encourage more social interaction and support within the group.

### **Outcomes and next steps**

The demand for in person classes has been clear as both the Hertford and Croxley classes have grown to have 10-20 participants each week. The groups find the in-person sessions motivating and incredibly beneficial for their health and fitness. One member said *"I have learned a lot about the type of exercise that is most beneficial for me. Beth makes the class enjoyable with her positive attitude"*.



The online programme has been popular amongst people struggling with mobility or fatigue as it allows them to build up their strength and fitness from the comfort of their home. People who are working have also felt the benefit as the classes are recorded so available for people to watch and follow along with in their own time.

I will continue to strive to keep our participants engaged and motivated in the classes. This includes creating monthly achievable challenges, hosting meet ups and introducing mash-up weeks every 6-12 weeks as a chance for the class to mix things up and try some new exercises.

I believe that with exercise, there is no one size fits all approach. However, there is something for everyone. I aim to support people with Parkinson's to find the exercise that challenges them, suits their physical and clinical needs, helps them to achieve their goals and most importantly that they enjoy.