Final category: 1 Innovation in practice

10

How to provide cognitive rehabilitation for people with Parkinson’s when face to face contact is limited

Debra Gallant, Claire Ward
South Tees NHS Foundation Trust, Middlesbrough, United Kingdom

Abstract

Objectives:

Short term: How to support those newly diagnosed with Parkinson’s Dementia during Covid -19

Long term: Establish if the Home Based Memory Rehabilitation (HMBR) programme for dementia can be benefit people with Parkinson’s and their family

Intervention:

I have been researching available evidence for cognitive rehabilitation for Parkinson’s Dementia for some time and after attending a Masterclass for the Home Based Memory Rehabilitation (HBMR) programme some years ago I questioned its use for Parkinson’s Dementia.

I gained permission in March 2020 to adapt the resources for Parkinson’s from the creator of the programme Mary McGrath OT based in a Memory clinic in Belfast and also those who piloted the program with people with dementia in Scotland Alison McKean OT and Elaine Hunter on behalf of the NHS Scotland and Alzheimer Scotland.

Outcomes

When carrying out an Occupational Therapy assessment via video or telephone call during the first Covid-19 lockdown period I realised I needed to move quickly to support patient’s cognitive needs. Especially if their goal was to improve their day to day memory, specifically (a) remembering where they had put things, (b) remembering what someone had told them or (c) something they had to do.

I adapted these resources for those with Parkinson’s and a Speech and Language Therapy colleague Poppy Larkin helped me to complete the section on communicating with someone with Parkinson’s. I then emailed or posted this 48 page booklet to patients and their families.

What did you learn?

People with Parkinson’s and their family members who received a copy were asked for feedback and reported that it was ‘*easy to read and implement*’ and it was ‘*helpful in improving their understanding*’ of how thinking and concentration is affected in Parkinson’s.

Next Steps

To implement a formal pilot of this programme for people with Parkinson’s.

People with Parkinson’s participating in the programme will be asked to evaluate it pre and post Occupational Therapy intervention.

Key questions to be asked:

Are they still using the strategies taught after 3 months?

What have they found most helpful about the programme?

Do they feel that their family now communicate with them any better?

Do family members now understand how cognitive changes in Parkinson’s affect their loved ones?

If the programme is found beneficial then the next step will be to create a professional resource booklet to share with other Occupational Therapists to enable them to provide cognitive memory rehabilitation for people with Parkinson’s.

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Advance Care Planning in Parkinson's in West Berkshire

Apurba Chatterjee, Nida Butt, Maha Khwaja, Carrie James, Helen Avery
Royal Berkshire NHS Foundation Trust, READING, United Kingdom

Abstract

OBJECTIVE(s): Advance Care Planning (ACP) in Parkinson’s enables patients to articulate their preferences for medical and social care when treatment becomes ineffective and dementia progresses.We wanted to review ACP completion in Parkinson’s patients who had passed away in 2017 at the Royal Berkshire Hospital and develop a referral pathway for ACP in complex Parkinson’s.We wanted to record discussions in a formal template and share with paramedics and General Practitioners via ADASTRA (electronic patient record system) to provide holistic care in Parkinson’s.

INTERVENTION: We completed a retrospective audit to review hospital deaths in Parkinson’s in 2017 and ACP completion.An Advanced Parkinson’s study day was organised on December 18th, 2018 where a Neurologist, Parkinson’s Nurse,Geriatrician and Palliative care shared their views on ACP. A GP survey was conducted on the management of ‘complex stage’ of Parkinson’s and ACP. A Trust guideline for referral of Parkinson’s patients for ACP was developed and published.We communicated this TRUST wide via teaching sessions, screen savers and Posters.An electronic referral for ACP assessment and a template for ACP assessment was developed by us. GP letters were generated on the electronic system.We conducted a patient survey on ACP in Parkinson’s.

OUTCOMES:

ACP was not completed in any of the 38 patients who had passed away in hospital in 2017.87% had reduced mobility,45% had dementia and swallowing was impaired in 42%.19 GPs responded to our survey and 100% were in favour of ACP completion in patients with advanced disease.79% felt this should be completed by a specialist doctor or nurse.34 patients and carers responded to the survey.41% had prior knowledge of ACP in complex Parkinson’s.62% were interested to discuss end of life care in advanced stages.68% were in favour of involving palliative care team in their future care. Following our successful interventions in 2019,**40 ACP have been completed till now** (despite the COVID 19 pandemic).60% of these patients have passed away. 83% of them have passed away at home/care home whilst only 17% passed away in hospital as they were undecided about their ‘preferred place of care’. As per the wishes of the patients ‘tube feeding’ was not considered in any of the patients.

We have presented our project at the **regional UK Parkinson’s Excellence Network meeting(Thames Valley) on the 29th of June.** Abstracts were published at the International Movements disorders meeting in 2020.We are planning to meet primary care colleagues and paramedics to improve the ACP pathway to consolidate the holistic care for frailer patients with complex Parkinson’s.

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The Parkinson’s Hub: an integrated care pathway for people living with Parkinson’s and frailty

Thomas Mace[1,2], Samantha Clark[1,2], Jane Curran[1,2], Tracey Woodrow[2], Chris Emmerson[3]
[1]Hull University Teaching Hospitals NHS Trust, Kingston-Upon-Hull, United Kingdom. [2]City Health Care Partnership, Kingston-Upon-Hull, United Kingdom. [3]NHS Hull CCG, Kingston-Upon-Hull, United Kingdom

Abstract

Objective: Our aim was to create a truly integrated pathway for patients living with Parkinson’s and frailty in Kingston-Upon-Hull. Parkinson’s UK and local MPs highlighted the changing needs of these patients were going unmet. A focus group of Parkinson’s UK members with their partners/carers identified the following needs: education, quick access to specialists, expertise from healthcare professionals and quicker medication changes.

Intervention: We have worked with Hull CCG to create a community-based multidisciplinary-led service that offers Comprehensive Parkinson’s Assessments. Colleagues from a variety of employers work together as one team. The assessment was influenced by the non-motor questionnaire, Parkinson’s UK Audit and Comprehensive Geriatric Assessment. The themes of the assessment include:

General Health

Nutrition, swallowing, speech issues and oral health

Cognition, mood, neuropsychiatric, sleep and impulsive compulsive disorder assessments

Continence and bowel function

Movement, motor-symptoms and falls

Bone health

Function and pain

Medication review

Environmental and carer requirements

Future care wishes

Signposting to charity initiatives

The assessment starts in the person’s home. This includes an environmental, carer, neurophysiotherapy and usually occupational therapy assessment. Social services review is offered with routine or “crisis” response available. The patient then attends the purpose-built integrated care centre designed for people with frailty, although domiciliary and care home visits are also performed. Visitors are offered complimentary drinks, snacks and lunch. Vital observations, ECG and blood tests are performed. A pharmacy technician reviews medication concordance and logistics, considering cognitive and dexterity ability. The multidisciplinary team (MDT) gathers each clinic (twice per week) to highlight patient's difficulties. The patient is reviewed by the consultant, with consideration of the non-motor questionnaire and a personalized plan is created. After, the plan is reviewed, responsibility for actions assigned and

shared with the patient and GP. The pharmacy technician ensures medication recommendations are actioned promptly. Urgent and routine follow-up is offered by the most appropriate team member, depending on patient need. Concerns about patients are discussed promptly in the MDT meeting to ensure speedy support. The MDT coordinator is the single point of access, arranging appointments and referrals.

Education sessions have been delivered to community doctors and allied healthcare professionals whilst lessons learnt have been shared with the Parkinson’s UK Excellence Network and published in a journal[1].

Outcomes and next steps: Feedback demonstrates patient expectations are realized with “Friends and Family” ratings of 96% very good and 4% good. Future ambitions include audit, closer working with mental health teams, developing a Clozapine service, developing our knowledge, and sharing learning of integrated MDT working.

References: (1) Mace T, Peel C. ACNR 2020;19(4):38-41

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GET IT ON TIME! A Quality Improvement Project to Improve the Administration of Parkinson’s Medications in the Emergency Department

Anju Menon, Rob Skelly, Barry Evans, David Hodgson, Sarah Midgley, Lisa Brown, Azaad Jameel, Esther Kirk
Royal Derby Hospital, Derby, United Kingdom

Abstract

Objective: Our aim was to make sure all patients with Parkinson's get their tablets on time in a busy emergency department. It is important to give Parkinson's tablets as soon as they are due[1] because when given late it can worsen physical and mental health and increase hospital stay.[2]

Intervention: In August 2020, we formed a project team that included doctors, nurses, pharmacists, and specialist Parkinson's nurses. Our planning phase lasted for 6 months where we collected information on 150 patients with Parkinson's. We carried out surveys, used flow charts, and created idea boards to help us understand the different reasons and solutions for this problem.

In February 2021 we introduced our first action plan, to teach staff about the importance of Parkinson’s tablets being given on time. We distributed weekly newsletters, led small group teaching, and placed posters to educate staff.

We also made an informational video with members of our department, which was shown at staff handovers. We appointed ‘Parkinson’s Champions’ and held tea time chats which helped to spread awareness about our project.

As part of the second plan, we used stickers on patient charts to easily identify patients with Parkinson’s. This helped remind staff that Parkinson’s tablets needed to be given to them on time.

We also improved the stock of tablets and now keep the usual Parkinson's tablets in our drug cupboards. We anticipated that this would improve the timeliness of tablet administration.

Outcome: Before this project, only 55% of patients with Parkinson’s received their tablets in the emergency department, of whom only 30% got their tablets on time.

By May 2021, nearly all (96%) of patients received their Parkinson’s tablets in the department. We also reduced the delay in receiving tablets from approximately 2 hours, to less than 0.5 hours (18 minutes).

Next steps: We are going to keep making things better and will continue to monitor how we do. Our project has been shared in the hospital's newsletter as an example of good practice. We received excellent feedback on our educational video which staff found highly motivating and we plan to start similar projects in other parts of the hospital.

References[1] National Institute for Health and Care Excellence. Parkinson’s disease – Quality standard [QS164]. February 2018. www.nice.org.uk/guidance/qs164/chapter/Quality-statements

[2]Low V, Ben-Schlomo Y, Coward E et al. Measuring the burden and mortality of hospitalization in Parkinson’s disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009–2013. Parkinsonism Relay

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Home Based Care for Parkinson’s

Camille Carroll[1,2], Emma Edwards[3], Sue Whipps[4], Martha Holley[5], Jemma Inches[1], Jane Rideout[6], Sue Bentley[1], Georgie Gilbert[1], Emma King[2], Tracie North[2], Joe Langley[7], Ursula Ankeny[7], Mat Swabey[1]
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Abstract

Objective

People with Parkinson’s (PwP) should be seen by a specialist at least every 6 months, but often wait more than a year; it is difficult to be seen more urgently. Getting to clinic can be stressful fro PwP, and staff are frustrated at not providing good quality care. We have developed a new care pathway, tailored to the needs of individual PwP, supporting their ability to manage their Parkinson’s, making sure they are seen by specialists when they need to be seen and using technology to monitor them at home.

Intervention

With PwP and care partners (CPs) we co-produced the Home Based Care (HBC) pathway, put it into action and evaluated how it worked. In 2019 we held 6 workshops to develop HBC, including resources provided to PwP to support their care; these included a Parkinson’s passport, a card deck to support their understanding of Parkinson’s, and information about how to manage Parkinson’s symptoms and how to trigger a healthcare contact. We continually asked for feedback to improve the pathway.

The pathway started in Oct 2019 and is ongoing. PwP and their CPs are provided with a pack and invited to a training session. They are able to request healthcare contacts when they need one, and are monitored every 6 months using the wrist-worn Parkinson’s Kinetigraph watch and questionnaires. By May 2021 we had 146 PwP on HBC. In Jan 2021 we evaluated the first 111 PwP.

Outcomes

Patient experience

After 6 months on HBC, PwP felt more involved in their care, listened to and treated as an individual, and had improved understanding of their Parkinson’s and when to seek help. PwP and CPs felt more in control, empowered and supported. PwP not on HBC no longer had appointments delayed.

Staff experience

Staff involved in HBC had improved mental wellbeing, despite the challenges of COVID-19. Staff felt

more valued and supported, with more control over their workload.

Symptoms and quality of life

All PwP motor and non-motor symptoms that we measured were improved after 6 months of HBC. Quality of life was maintained.

Next Steps

We are continuing to improve and refine HBC based on PwP/CP feedback and evaluation. We have shared our experience of HBC via social media and blogs (https://bit.ly/3gxn4EK; https://bit.ly/3q6Q2P5); we have presented to PwP groups in England and Scotland, and at national and international conferences. We are writing up our project to be published in a medical journal, and are working with others to spread our pathway to other Parkinson’s services across the NHS.

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Adaptation and Innovation of PD Warrior, from the world locking down physically to opening up to the world virtually.

Alistair Macfarlane, Kev Fry
PD Warrior - Bristol, UK, Bristol, United Kingdom

Abstract

Objective: Enabling our PD Warriors to continue exercising as the UK enters lockdown.

Intervention: Since establishing PD Warrior in Bristol in 2018, we have built a large community of people living with Parkinson’s. PD Warrior is a high effort level exercise programme targeted at slowing down the progression of Parkinson’s symptoms.

With the shutting down of life as we knew it due to COVID-19, lockdown meant that our regular participants would not be able to attend classes. We thought fast and with the emergence of Zoom came up with a way to reach out to those participants. Within 2 weeks of lockdown starting and gyms closing, we had developed 3 online classes for our participants to attend during the week. This not only ensured that they could continue to be active, but also to keep up some normal semblance of life, support, and contact with others in the same situation. Since starting online classes, we have welcomed more than 60 participants who regularly join the classes, not only from Bristol, but we have participants from across the UK, South Africa, and as far as Australia. We have offered 3 classes a week for over 16 months now and we will continue to do so beyond the pandemic. Participants have commented on what a vital life line this has been for them, with participants quoted as saying “without PD Warrior Bristol I don’t know how I would have got through lockdown with my Parkinson’s still manageable” and “Their work has enabled me to quite simply carry on with my life. They have been vital for my vitality!”. We decided we needed to expand the online platform when the lockdowns showed no signs of easing and we were receiving a large number of enquiries to join the online classes. Alistair’s mum received a diagnosis of Parkinson’s in late 2020, and with her help we successfully trialed the 10 week beginners course online, resulting in us having run 3 back to back courses since. Many of these new participants have joined the regular classes, Alistair’s mum included.

Outcome and next steps: With the innovation of PD Warrior moving online, we have ensured that those living with Parkinson’s during the restrictions in the UK and further around the world, have had access to bespoke exercise in the comfort of their own homes. The outcomes have been outstanding and have made the transition to online hugely successful. But above all, it has offered a vital lifeline to those living with Parkinson’s during this extremely difficult time.

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Final category: 1. Innovation in practice

12

Application of new technologies in a moment of crisis: a lesson for the future

Barbara Fort, Sarah Jackson, Samantha Moore
Royal Devon and Exeter Hospital, Exeter, United Kingdom

Abstract

Objective(s): like other NHS services, the Royal Devon and Exeter Foundation Trust has faced the risk of the COVID-19 pandemic compromising the care we provide our Parkinson's patients. During this time, two members of our team were also redeployed.

We are proud of the high quality Parkinson's services we offer in Exeter, which comprises a Parkinson's Outreach Team with two non-medical prescribers and a Parkinson's cohort ward. The Team also runs Parkinson's Awareness courses, educational sessions for local GPs and trainee doctors, as well as Duodopa Masterclasses. We also run a local apomorphine service and a clozapine service. The goal was to find an efficient way to continue to provide these services despite the challenge of the pandemic.

Intervention: the Team in Exeter rose to the challenge, we proved flexible and innovative reconfiguring the service, making the most of the technology available and adapting it to its needs. This included PKGs to monitor motor symptoms remotely, videoconferencing softwares and telephone consultations. Some of the systems had never been used before in this setting. An example is the electronic record system MyCare, which was introduced to the Trust in October 2020. Staff had to face the additional challenge of mastering its use, at the same time as avoiding negative impact on quality of care. Face to face appointments needed to be clinically justified, so patients were triaged and allocated appointments accordingly. Apomorphine sessions and integrated Parkinson's meetings were carried out via videoconference. This allowed to invite eminent speakers from more remote locations.

Outcomes and next steps: despite redeployment of two members of the Parkinson's team, we remained accessible and reactive to referrals. Clinic continued to run via different modalities. PKGs were performed as remote patient reviews. The community Parkinson's team played a key role facilitating follow up clinics, liaising with patients that otherwise may have attended hospital for minor Parkinson's complaints. The Neurology Team also rose to the challenge covering the Parkinson's cohort ward. With 229 patients seen over 6 months, the outreach Team was able to continue their supportive role for inpatients and ward staff.

MyCare allowed the introduction of a flagging system to track patients in the acute setting as well as providing seamless communication with the community team. Ultimately, patients will have access to their own medical records enabling one-safe software for communication. The efforts of the service were recognised with a '*Learning from Excellence'* award in June 2021. Moving forward, we will continue to use these systems with a view to improving clinical effectiveness and to optimise engagement from patients and professionals.

17

Empowering People with Parkinson's - MyParkinson's App

Biju Mohamed[1], Sarah Page[1], Stephanie Wells[1], Chris Thomas[1], Ruth Morton Lewis[1], Tracy Williams[2], Sandra Mahon[2]
[1]Cardiff and Vale University Health Board, Cardiff, United Kingdom. [2]Cardiff and Vale University Health Board, cardiff, United Kingdom

Award categories

1. Innovation in practice

Abstract

Background:

The Covid-19 pandemic caused significant disruption to the delivery of specialist services for people with Parkinson’s. During the initial 8-week period of lockdown, we received over 280 calls seeking advice on a range of issues on the clinic helpline number. A detailed analysis of these data reveals a significant proportion of these enquiries were seeking generic information about Parkinson’s. People with Parkinson’s (PwP) felt they were missing out on medical and nursing support, in addition to experiencing reduced access to services and therapies. With increased virtual and telephone consulting, it was difficult to provide PWP with written and information

Objectives and Intervention:

In response to these issues we wanted to improve on:
1. Promoting self-management in line with NICE guidance for active participation in care.
2. Providing post-diagnostic and ongoing information about Parkinson’s in different formats including written and audio-visual- recognised in repeated PUK audits
3. Improve access to the Parkinson’s MDT - again recognised in PUK national audits

Working together with PwP, we gauged interest in a web application (an ‘App’) that would be easily accessible to promote self-management, immediate access to information and access to multidisciplinary team information in audio-visual format. Overwhelmingly positive feedback led us to perform a review of access to internet and technology in our cohort. We established that 80% of PwP had access to an internet enabled device and others would have a family member who could access it on their behalf irrespective of age and socio-economic background in our limited study. The multi-disciplinary team of clinical experts then collaborated with an ‘expert by experience’ Parkinson’s advisor to tailor content for the App.

Outcomes:

We developed My Parkinson’s (www.myparkinsons.org.uk), an interactive web-based resource designed for Parkinson’s service users in Cardiff and Vale University Health Board. The app has written content and a series of short videos introducing the different members of the multi-disciplinary team with explanations about common symptoms in Parkinson’s and self-management strategies.
The app also provides information about relevant local and national services like Parkinson’s UK. The app has been designed to be adaptable to any Parkinson’s service and locality.

Empowering PwP with information about their condition and MDT support available, they will be able to direct their questions and concerns to the appropriate member of the multidisciplinary team improving care.

We are currently assessing feedback from a limited number of PwP and their loved ones/carers to fine-tune the content over the next few weeks prior to recommending it routinely in our service.

21

PDPower Online by Annie Rainbow Physiotherapy

Annie Rainbow
PDPower, Wendover, United Kingdom

Abstract

Introduction

I worked as an NHS physiotherapist, with special interest in Parkinson’s, for fifteen years and saw the benefit of regular exercise to people with Parkinson’s (PwP). Having set up exercise classes for PwP in my NHS role, it became apparent that long-term classes were not available to them once their NHS treatment finished.

Objectives

To establish weekly PDPower exercise classes in the South Bucks area offering long-term exercise provision and education for PwP and their families.

Intervention

The classes proved extremely popular, and the importance of community to members was immediately obvious. I created a PDPower Online information and social platform via Mighty Networks to complement the classes and encourage interaction and knowledge-sharing between the members outside of the classes. As demand grew, I was lucky enough to recruit two invaluable team members who have helped us grow and ensure good quality, safe classes; they brought unique skills which has allowed us to provide Boxfit, Nordic walking and weights classes.

When lockdown happened, I was keenly aware of how important exercise, community and advice had become for the 60 members attending classes. We faced a steep learning curve, but helped and supported by our local Parkinson’s UK branch, friends and family, we quickly moved PDPower face-to-face classes to Zoom and were running three classes/ week online by end of March 2020.

Outcomes and next steps

PDPower members' need for community and contact through the pandemic was confirmed immediately by the near 100% attendance of over 40 people, three times a week.

The PDPower community has grown together through the introduction of regular challenges and fundraisers to help the local branch, in addition to helping people focus on their physical capabilities. We have now raised £5000+ in the past three years to help the local branch.

The challenge of the last 18 months has also turned into positives. Recorded classes on YouTube, workshops based around balance and posture, and goal-setting have combined to drive more adherence to regular exercise for the members.

We now aim to continue the Zoom journey, alongside restarting some face-2-face classes, as it has helped people attend more regularly.

I am so proud to be part of this large team of PwP and my fantastic colleagues. I am continually surprised and inspired by how far we can push PwP regarding exercise. This past 18 months has demonstrated their amazing resilience, physical and mental strength, and dedication to a life with exercise, helping slow their Parkinson’s progression. It is an absolute pleasure to work with such a great team of people.

31

Alistair Macfarlane - The PD Warrior instructor who welcomed people living with Parkinson's into his living room for virtual exercise and community support.

Alistair Macfarlane
PD Warrior - Bristol, UK, Bristol, United Kingdom

Award categories

1. Innovation in practice

Abstract

Objective: Alistair Macfarlane taking PD Warrior online

Intervention: I am passionate about helping improve the quality of life of those living with Parkinsons and other health conditions. My job as Exercise Referral manager across 3 sites in Bristol ensures that I help those with all types of physical and mental challenges. When lockdown was announced in the UK, I knew I needed to act fast to ensure those individuals relying so heavily on my PD Warrior classes could continue. With the emergence of Zoom, I made the decision to see if we could offer our regular PD Warrior classes to our participants virtually. There were many logistical issues that needed ironing out, but I knew that we needed to act fast to reach out to our participants. Within two weeks we had started our classes online offering 3 lunchtime classes a week. I was put on furlough at the start of lockdown and realised that this innovation of our PD Warrior course would be as important for me as my participants, not only for routine, but for social contact. A great deal of our participants have commented over the 17 months that we have offered these online classes, that it has been a lifeline for them, not only ensuring that they continue to carry out the exercises that ensure that they can live their day-to-day lives to the fullest, but also for the social contact with familiar faces. I now offer a weekly recording so those who are unable to attend the Zoom classes live can have a structured class to follow at a time that suits them.

During lockdown, my mum was diagnosed with Parkinson's. I was determined to help my mum, and I used her to trial our 10 week induction course online. The success with my mum meant I could open this up to the many participants enquiring to join our online classes. Since then we have run 3 courses feeding more participants into our weekly classes.

Outcome and next steps: Restrictions may have eased, but the online classes have become part of our weekly routine, with many participants preferring the online platform instead of travelling to the in classes at our centres. We will continue to offer these classes, plus the 10 week course online. I have started to look at what further possibilities the virtual world could offer for our courses, I am excited to see where the next step could take us.

Alistair Macfarlane

Final category: 2 Sharing learning and education

5

To develop and evaluate an e-learning module delivering training to healthcare staff in the management of medications in hospital in-patients with Parkinson’s.

Rachael Matthews, Kevin Johnson, Patsy Cotton, Carol Miller, Alexander Thomson
Salford Royal Hospital, Salford, United Kingdom

Abstract

Objective

It's of vital importance patients with Parkinson’s receive medication correctly and on time. Medication management for in-patients with Parkinson's is challenging for hospital-based healthcare professionals. Education in prescribing and administration of medications is limited by rota time-constraints, high staff turnover and busy clinical jobs. Previous local approaches included face-to-face ward-based and seminar teaching. These proved unsuccessful, with invariably poor uptake by staff and limited carry-over of learning. We utilised feedback acquired from previous approaches and felt an accessible online learning module would be the best educational tool.

The aim of this project was to develop and evaluate an e-learning module, delivering training to healthcare staff in the management of medications in hospital in-patients with Parkinson’s.

Intervention

Members of a Parkinson’s multidisciplinary team in a hospital Movement Disorders service worked collaboratively to develop an on-line training module. Supported by IT staff with the necessary expertise, the module was designed to deliver practical, factual information. Education and learning was enhanced by interactive elements and short video clips of members of the MDT and included, importantly, a person living with Parkinson’s. Pre and post-module assessments were embedded to enhance learning. Following pilot testing, the module was rolled out with further qualitative and quantitative feedback gathered from key user groups.

Outcomes and next steps

Feedback was sampled from 24 individuals across a variety of disciplines and levels of training and experience using a questionnaire. Using a modified Likert scale, the overall utility of the module scored a mean of 9.46/10 (1 = completely useless, 10 = highly effective).

The three most common take-away messages from the e-learning module were contra-indicated medications (41.7% respondents), the importance of timely medication delivery (37.5%) and non-oral options (33.3%).

The most effective design element of the module was the pre and post-module quiz (25% respondents).

Development of an easily accessible on-line education module was warmly received by key members of healthcare staff looking after this complex patient group. This training method overcame previous training barriers which Movement Disorders staff had encountered. Feedback highlighted the emphasis and reinforcement of several core messages around prescribing and administration of medication for in-patients with Parkinson’s.

Further steps would be to extend the e-learning module to a greater number of healthcare staff, including the possibility of making this a compulsory module in staff mandatory training. Following this, an audit of the number of prescribing errors amongst inpatients with Parkinson’s and comparing this to

our previous data, would be of use to evaluate if the e-learning module has had a positive impact on clinical practice and patient care.

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The Parkinson’s Excellence Network Exercise Professionals Hub: A collaborative platform for sharing learning and practice to improve exercise provision for people with Parkinson’s

Bhanu Ramaswamy OBE[1], Beccy Oliver[2], Katherine Baker[3], Julie Jones[4]
[1]Sheffield Hallam University [Hon Visiting Fellow], Sheffield, United Kingdom. [2]Thorpes Physiotherapy, Sandhurst, United Kingdom. [3]Northumbria University, Newcastle, United Kingdom. [4]Robert Gordon University, Aberdeen, United Kingdom

Abstract

Exercise is vital in Parkinson’s management; people with Parkinson's value seeing professionals with condition-expertise.

The Exercise Professionals Hub was launched in 2015 as a UK-wide network through the Parkinson’s Excellence Network. It aimed to raise the profile and quality of exercise provision for people with Parkinson's by providing practical guidance/best practice for professionals working with this community.

The Hub reached out to professionals across the health, voluntary, sports and leisure sectors to share education and practical learning, generating ideas to improve exercise provision and improving access to exercise for the Parkinson population nationally as well as facilitating implementation of research findings to inform practice.

The initial 15-strong membership has grown to 316 registered members since it was established, many of whom connect into a wider audience. Hub membership now comprises exercise professionals, occupational therapists, a person with Parkinson’s, physiotherapists, medical professionals and service provision managers, operating with the support of the Parkinson’s UK staff.

As volunteers, we are limited by time, resources and geography yet in addition to facilitating the sharing of practice through our Blogs and Basecamp chats, the Hub has been consulted by Parkinson’s UK to enable education and learning to be realised through the collaboration of content for the charity’s ‘Exercise’ website pages and wider projects e.g. the ‘We are Undefeatable’ campaign.

The shared ownership ethos of the Hub encourages different levels of members’ engagement, engendering ideas and sustaining Hub activity; our wide audience also ensures a far-reaching impact of Hub output.

For example, on publication of a co-developed Parkinson’s Exercise Framework for professionals (2017), participants at the 2018 Excellence Network Conference requested further explanatory material. An updatable teaching template on exercise benefits for people with Parkinson’s was designed, altered, and ratified by Hub members at the 2019 Hub Conference, then used to educate other professionals and people with Parkinson’s.

In 2020, in response to the Covid-19 pandemic, Hub members agreed basic guidance for professionals delivering exercise remotely, plus provided Parkinson’s UK with a library of videos as a home-based exercise resource.

One outcome of the Hub members survey of learning needs established a series of well-attended monthly Hub Zoominars during 2021 on a wide variety of exercise-related topics, replacing the annual Hub Conference.

Members report that Hub activity addresses an educational and networking opportunity for a wide professional audience that isn’t met in any other way. They appreciate both the information provided and the opportunity to network so they can support the delivery and development of high-quality exercise-

based services for people with Parkinson’s.

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The Development of a Parkinson's Specific Falls Risk Assessment Tool

Claire Ward, Debra Gallant
South Tees NHS Foundation Trust, Middlesbrough, United Kingdom

Abstract

Objective

To ensure that all therapists assessing people with Parkinson's who are at risk of falling undertake a comprehensive assessment ruling in Parkinson's specific risk factors.

Intervention*:*

We reviewed the Falls Critical Appraisal documents regarding available evidence for manging falls in Parkinson's and agreed that we needed to design a more suitable falls tool ruling in Parkinson's specific risk factors.

We liaised with all relevant bodies, local falls team services and discussed the need for this tool at length in the Parkinson Special Interest Group that we facilitate locally bringing together health, social care and mental health AHP with a special interest in Parkinson's. We then designed the tool clinically and alongside our Information Technology Department who could then apply it to the electronic documentation we use. A paper based tool was also been created to enable those staff not connected with the same electronic notes to carry out the assessment too.

We offer annual Parkinson's Awareness training for all qualified staff alongside their inductions and we will now educate them how to use the tool in this training.

Outcomes

Our tool has successfully been added to the electronic documentation system and the hope is that it will soon be used by all community therapy services.

What did you learn?

Falls in Parkinson's must be addressed by Occupational and Physiotherapists together; the need to consider the impact of the home environment and cognition is paramount as standard falls exercise programmes that focus on balance alone are not suitable in advanced Parkinson's. Multifactorial Falls tools also do not consider the physical factors that need to be ruled in for Parkinson's such as freezing of gait, dyskinesia and motor fluctuations.

Our tool incorporates all these factors and is an education tool at the same time. Staff greatly appreciate our support and advice when assessing patients with Parkinson's as the local specialists. However, our goal is to ensure that all qualified Physio and Occupational therapists locally have the support, skills and tools to assess and support people with Parkinson's.

Next Steps

To ensure that all community therapy staff are able to access and are fully trained in using the Parkinson's Specific Falls tool.

To evaluate the benefits of the tool for staff and in reducing admission to hospital for people with Parkinson's following a fall and if any changes are needed to tool.

Reference

Parkinson’s UK Critically Appraised Topic (CAT) supporting the Clinical Summary: Parkinson's and falls.

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14

Formation and development of the Parkinson’s Specialist Pharmacy Network (PDSPN) to educate and upskill pharmacists and other healthcare professionals in the management of Parkinson's

Janine Barnes, Stephanie Bancroft and the PDSPN steering committee

Janine Barnes[1], Stephanie Bancroft[2]
[1]Dudley Group NHS Foundation Trust, Stourbridge, United Kingdom. [2]NHS North West London, London, United Kingdom

Abstract

Objectives

We formed the Parkinson’s Disease Specialist Pharmacy Network (PDSPN) in October 2018 to upskill pharmacists and their teams, in the management of Parkinson’s. This is particularly important because pharmacists are frequently the first point of contact for people with Parkinson’s (PWP’s) and medication is often complex and of paramount importance to them.

In 2019, several areas of improvement that could assist management of Parkinson’s were identified by a Parkinson’s UK Audit Report. The work of the PDSPN aims to facilitate improvements in these areas:

As pharmacists we aim to improve medicines management and support for PWP’s by upskilling all professions involved in their care.

Intervention

In 2018 Janine Barnes formed and currently chairs the PDSPN Steering Committee with other highly experienced pharmacists and we have PWP’s representation too.

The committee meets regularly, to oversee the running of the network and formulate our plans to host regular conferences. Since our first conference in October 2019 we have grown to 270 members across the UK. Our initial conference had excellent delegate feed-back, with the presentation from the PWP’s being particularly well received and very powerful.

We send regular newsletters and held a Parkinson’s quiz for World Parkinson’s Day on April 11th 2021, which was very popular.

Outcomes and Next Steps

We are now working on the format of our next conference to be held early in 2022. Our inaugural conference was dedicated predominantly to pharmacists and their teams and we also had representation from PWP’s. We are now planning to include other healthcare professionals so that education about Parkinson’s can be shared more widely amongst all the professions that are involved in the care of PWP’s. We also plan to host workshops and interaction sessions within the conference.

Our next conference will incorporate sessions on the new primary care networks[1] (PCN) and education for the new roles that pharmacists and physiotherapists are taking to improve best practice. Opening the conference up to other professions will also be helpful for specialised multidisciplinary team working.

The PDSPN plans to support educational materials to help pharmacists and other professionals post prescribing qualifications.

Our intention is to share education and increase understanding regarding Parkinson’s medicines management amongst other healthcare professionals involved in the care of PWP’s to improve multidisciplinary team working[2] and professional relationships in the care of PWP’s.

References

1.PCN-https://www.england.nhs.uk/primary-care/primary-care-networks

2 .NICE guidelines NG71-https://www.nice.org.uk/guidance/ng71

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18

Parkinson's Medication - Get it on Time!

Jennifer Dawber, Liam Kind
Lancashire Teaching Hospitals, Preston, United Kingdom

Abstract

Objectives

The overall objective was to improve the knowledge and understanding of staff within Lancashire Teaching Hospitals NHS Trust of why medications need to be given on time when people with Parkinson’s enter our hospitals. An audit highlighted that we needed to address the need for medications to be given on time.   Initially face to face teaching sessions were delivered but it was identified that we needed another way to reach as many members of staff as possible. We therefore developed two E Learning courses one for members of staff that need a more in-depth knowledge of Parkinson’s medications and another for staff who do not dispense medications.

Intervention

Initially the eLearning packages were designed to be a good educational tool for staff working for Lancashire Teaching Hospitals. The Parkinson’s Nurses at Lancashire Teaching Hospitals worked closely with the Trust’s Blended Learning Team, over a six-month period, to produce two engaging interactive eLearning packages. These eLearning packages incorporated information and videos from Parkinson’s UK with local information, graphics, animations, videos and photos. These high-quality courses have been well received by the Trust’s staff many of whom have left positive feedback upon completion of the course including: “An interesting and insightful course outlining the consequences of giving Parkinson's medication late.”; “I found the patient video particularly moving and I shall emphasise the importance to my future student nurses.”; “Very interesting course with lots of information that will be invaluable in helping me to care for people who have Parkinson's” and “As a pharmacy technician I found this course very important to complete as it highlights the importance of prioritising Parkinson’s medication when dispensing/ordering”

Outcomes and next steps

Staff within Lancashire Teaching Hospitals Trust now has a greater awareness of Parkinson’s. We know from feedback from patients that there has been a greater understanding of Parkinson’s within the Trust. We have also noted from reviewing inpatients that delays in medications being given on time have been reduced. We will soon be re-auditing Medications on Time again within the Trust and are excited to see how far we have progressed.

Following the successful publication of the course the eLearning package has been adapted by the Blended Learning Team and shared by the Parkinson’s UK Excellence Network, so that it can be imbedded into other Trusts within the UK, this has been a massive achievement for our team and our Trust a whole.

We continue to promote the eLearning within our Trust on regular basis; and we recommend that all staff complete it.

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25

Primary Care Pharmacist Support for People with Parkinson's (PwP) - Part 1 - Pilot Study of Community Pharmacy Medication Reviews

Shelley Jones
Kings College Hospital, London, United Kingdom. PDSPN, National, United Kingdom

Abstract

Objectives/Background:

The management of Parkinson’s usually includes life-long dopaminergic medications. The conditions progressive nature often necessitates increasingly complex medication regimens. The recent Parkinson’s UK audit highlighted medicines management, and workforce support, as priorities for improvement. Long term prescribing and supply of medicines is largely managed in primary care. PwP often see their primary care pharmacists more frequently than their specialist teams. Pharmacists working in the primary care setting have regular opportunities to review medicines and provide advice support and care for PwP.

Formal networks linking specialist pharmacists in secondary care with those in primary care don't exist. This forms a barrier to more joined up care and impacts confidence of primary care pharmacists who may each see relatively few PwP. Historically, community pharmacists were commissioned to provide Medicines Use Reviews (MURs) in England, although PwP were not a targeted priority. MURs are not part of the new contract, however primary care network pharmacists will continue to be supported in completing medication reviews, but again PwP will not be targeted.

Intervention:

Part 1 aimed to improve experience and quality of life for PwP by making them a target for pharmacist medication reviews in primary care and to improve support and networking across primary and secondary care for pharmacists working with PwP.

Building on the work of Stephanie Bancroft to promote Parkinson’s specific MURs in the community we worked with Parkinson’s UK and a corporate partner to pilot Parkinson’s specific MURs. We developed an educational programme, accredited by the Royal Pharmaceutical Society, and delivered it face to face. (This programme has now been adapted for online delivery to enable greater reach). Following completion of training and assessment pharmacists delivered MURs using tools and prompts provided. Pharmacists involved had a direct link to the specialist pharmacy team at a large teaching hospital for queries. The pilot methodology and outcome measurements were adapted following feedback from the CRISP patient group to ensure we were meeting the needs of PwP.

Outcomes/Future:

The results of the pilot were overwhelmingly positive. Twenty-four MURs were completed. PwP said they had gained a greater understanding of their medicines and felt other PwP would benefit. Pharmacists found them a positive experience and noted that PwP highlighted more complex issues than other conditions and had more confusion around their medicines. The pilot concluded Parkinson’s specific MURs were feasible, but a plan to make them sustainable and more widely available is needed.

Now undertaking a wider study to identify a sustainable model for primary care pharmacist involvement in medicines optimisation and support for PwP.

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Final category: 2. Sharing learning and education

4

Improving Experience and Outcomes for Patients with Parkinson’s admitted to a district hospital.

Natalie Sharp, Christopher Dyer
Leighton Hospital, Crewe, United Kingdom

Award categories

2. Sharing learning and education

Abstract

Objective

A small therapy team with a specialist interest in Parkinson’s looked at audit and service redesign to assess and implement changes for Parkinson’s patients at a district hospital with no specialist neurological therapy services.

Intervention

An audit has collated and assessed extensive data over 3.5 years for all patient discharged with Parkinson’s. 43% of all neurological patients at the trust have Parkinson’s over this period. Service redesign introduced a post for a frailty physiotherapist with a specialist interest in neurology. The risk of immobility, long lengths of stay, on time medication, and readmissions have been addressed. This is a work in progress and the therapy team has looked at improved care across the pathway, reducing length of stay, optimising outcomes, and reducing readmissions. Close collaborative working has developed throughout the trust and with the community/ outpatient therapy teams and specialist Parkinson nurse. A PD warrior exercise group has been implemented with collaborative inpatient and outpatient therapy involvement, to increase care and support across the pathway and for discharge from hospital. The therapy team have also developed links with other local trusts, specialist centres and external agencies. There has been a focus on early assessment, holistic management, early discharge with ongoing support, education to the multidisciplinary team within the trust. A specialist interest group has been developed with representation from the wider MDT across both the inpatient and community teams.

Outcomes and Next Steps

As a direct result of this implement of change, long term improvements in the care of Parkinson’s patients at the trust has been gained. Engagement with patients has seen improved patient and carer satisfaction. Ongoing education programmes, and access to specialist therapists in Parkinson’s is key to develop and sustain this service.

7

Co-Development of Parkinson's Awareness Audio Podcast for Nursing Students

Gary Mitchell[1], Susan Carlisle[1], Johanna McMullan[2], Amy Wong[1], Patrick Strark[1]
[1]Queen's University Belfast, Belfast, United Kingdom. [2]Queen's University, Belfast, United Kingdom

Abstract

Recent evidence has highlighted that Parkinson’s education for nursing students is often limited. To improve nursing students’ knowledge/attitudes to Parkinson’s Disease (PD), we co-developed an audio podcast to raise awareness about the condition. We used a co-design methodology and our team consisted of more than twenty people that included people living with PD, people who cared for those with PD, volunteers who provided support to people with PD, PD nurse specialists, nursing students and nurse lecturers from Queen’s University Belfast (QUB). We co-designed a 75-minute podcast comprised of three main segments that took the form of different nursing students hosting interviews with a person living with PD, a carer of someone with PD & a PD nurse specialist. These interviews were scripted (by the co-design team) to ensure that each speaker covered different learning outcomes.

Using mixed methods, we provided 332 student nurses with a validated pre and post questionnaire about their knowledge related to PD. Before listening to the podcast, students scored an average of 52.74% and after listening this rose to 80.07%. Using paired T-Tests, we determined statistical significance ($p<0.001$). Specific improvements in student knowledge related to PD diagnosis, PD treatments and the trajectory of PD. We also explored how the podcast had influenced student practice in the six months after listening (interview guide were designed by people living with PD). Four focus-groups comprised of a total of 35 nursing students took place. Using thematic analysis, two main themes emerged. The first theme was that the podcast helped students to empathise and understand the lived experiences of people living with PD. Students noted their surprise around the fluctuation of PD symptoms, their disappointment that people with PD experienced significant social stigma and their new confidence in supporting people with PD within their local community. The second theme was around how the podcast improved student care of people with PD, for example ‘getting medication on time’, the importance of PD nurse specialists and how to contact/refer patients to these services and how better support PD carers.

Findings are being written up for a healthcare journal. In autumn 2021, the Royal College of Nursing will be disseminating a link to the podcast amongst its 450,000 members via its E-Bulletin and Students Magazine. In the past twelve months, the podcast has been listened to by more than 1000 nursing students and it has also been embedded in both undergraduate/postgraduate nursing curricula at QUB. The podcasts were also freely launched to the public during Parkinson’s Awareness Week in April 2021.

Final category: 3 Person-centred approach

11

Parkinson's Care at Harrogate, Above and Beyond.

Rosaria Buccolerio, Ipshita Scarrott, Angela Horner, Angela O Connor
Harrogate District Hospital, Harrogate, United Kingdom

Abstract

Parkinson’s care, above and beyond

R.Buccoliero, A.Horner, A.O’Connor, I. Scarrott

Objective: Over the last few years the Harrogate Parkinson’s Team carried out 3 Parkinson’s person centred projects: 1) ‘Parkinson’s Medication on Time’ that aimed to enhance in-patient care; 2) an assessment of outpatient Parkinson’s services that optimised a holistic approach, and 3) Dr Buccoliero delivered a primary school education programme to increase awareness of aging/long term conditions in children.

Intervention: 1) ‘Parkinson’s Medication on Time’ project identified that in 2017 19.9% of Parkinson’s patients received their medications within 30 minutes and 42.9% were given over an hour later. In conjunction with the Parkinson’s nurses and Dr Scarrott, Geriatrician, Dr Buccoliero lead the team in a multifaceted Quality Improvement Project. This involved regular education sessions across all adult specialities. Our local Parkinson’s Charity was also involved in the implementation by providing ‘get it on time’ stickers, wall clocks, posters and alarm clocks to facilitate medication delivery.

2) To ensure the quality of our outpatient Parkinson’s care, Dr Buccoliero and her junior doctor undertook an audit of 237 patients who were seen in the first 6 months of 2020. Areas looked at were in line with highlighted areas from a previous NICE audit:

Our local Parkinson group also helped to put together ‘new patient’ leaflet packs to ensure patients were receiving information in an easily accessible, joined up manner.

3) The ‘Aging Awareness’ project was presented to school children aged 8-11. Since 2017, Dr Buccoliero delivered sessions in 8 local schools, to increase understanding of aging and long-term conditions including Parkinson’s. It involved:

Outcomes and Next Steps: 1) Our ‘Parkinson’s Medications on Time’ project showed a significant improvement after intervention. In 2019 there was a 48% increase in patients receiving their medications within 30 minutes and a 30% reduction in patients receiving medications over an hour late. Next steps, when out of the COVID pandemic, is to re-evaluate and refresh education.

2) In outpatients, in the three areas of enquiry, the Parkinson’s clinic was achieving rates of 99.5%, 100% and 100% adherence. At least half of the data was from pandemic months, when telephone clinics came into practise, highlighting our continued holistic, reliable and safe reviews despite COVID.

3) Written feedback obtained from the children after each aging session showed 98.5% of children judged the whole session to be good or excellent. Comments received stated that ‘it encouraged me to be more respectful’ and ‘taught me a valuable lesson’. The aim is to re-start post-COVID.

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MOVING MEDICINE: NEW RESOURCE TO HELP HEALTH CARE WORKERS SUPPORT PEOPLE WITH PARKINSON’S TO BE ACTIVE

Harriet Collins[1], Helen Dawes[2], Gus Mak[3]
[1]Moving Medicine, Edinburgh, United Kingdom. [2]University of Exeter College of Medicine & Health,, Exeter, United Kingdom. [3]SEM Northwest Training Programme, Manchester, United Kingdom

Abstract

Background:

Launched 16th October 2018, the Moving Medicine resource is designed to promote activity as an intervention for both primary prevention and long-term conditions such as Parkinson’s.

Moving Medicine is an initiative by the Faculty of Sport and Exercise Medicine UK (FSEM UK) in partnership with Public Health England (PHE)and Sport England(SE) to improve physical activity conversations across healthcare and support the routine delivery of physical activity support for all. The initiative’s main goals were to create a tool to help healthcare professionals sustain a change in clinical practice through improved knowledge, improved skills, an integrated system and a change in culture.

What we know:

- Awareness of robust evidence outlining the benefits of physical activity in the treatment and prevention of long-term conditions including Parkinson’s

- Many clinicians lack the knowledge, skills, and confidence to have frequent, high-quality conversations on physical activity behaviour change in clinical practice

- Routine integration of physical activity interventions is poorly supported by healthcare systems

What we have done:

Reviewed the up-to-date evidence base for physical activity in Parkinson’s

Shared evidence and listened to feedback from multiple sources

Using ‘knowledge into action’ framework, created a web-based resource for clinicians to have person-centred conversations based on 1 minute, 5 minute or more minutes, exploring both benefits and concerns the patient may have about being active and how to address these

Added signposting to national resources

Created Parkinson’s specific patient leaflets

Supported people in research.

What are the outcomes:

Puts people with Parkinson’s at the centre of the conversation

Equips healthcare workers to adapt advice and sign-posting given, based on the capability/ opportunity available to patients to influence and motivate positive behaviour change on an individual basis.

Ensures timely delivery of information, from diagnosis onwards

Supports people to take control to make the most of their life with Parkinson's

Links people to the right professionals to address their specific needs

Links with other services to make sure care is integrated and joined up

Uses evidence and education to improve standards of care.

Who has supported this work:

People with lived experience of Parkinson’s

Key stakeholders from the NHS, private and charity sector

Physical Activity and research experts

FSEM UK in partnership with PHE and SE

Module development team of experts in Parkinson’s and Sport and Exercise Medicine.

What next?

Launch on social media and via Stakeholders on World Parkinson’s Day 2021.

Moving Medicine to share this resource widely via conferences, webinars and presentations.

The website is accessed around the world and to date has had over 112,000 users.

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19

The development of virtual exercise sessions to help people living with Parkinson’s thrive, the Neuro Heroes way!

Laura Douglas, Anna Kharin
Neuro Heroes, London, United Kingdom

Abstract

Objective:

We are two neuro physiotherapists with 22 years’ combined experience. During the 2020 lockdowns Neuro Heroes was born, to give people with neurological conditions an opportunity to get active at home, with expertise from a neuro physio and motivation of a group surrounding them. We were determined to enable people with Parkinson’s to meet Parkinson’s UK exercise guidelines with confidence, remotely supported by a specialist.

Intervention:

Using an evidence-based approach, we have created online group exercise sessions to include exercises that help common difficulties in Parkinson’s, to try and slow symptom progression. Live sessions allow us to respond to individuals’ needs and adapt exercises in real time to different levels.

We piloted PD Power in October 2020, with the input of six people living with Parkinson’s. We wanted to include condition-specific exercise alongside strengthening and fitness. One participant says sessions are “very energetic...I appreciate the Parkinson’s-specific balance, facial moves and doing two exercises at once”. Sessions were developed using invaluable service-user feedback, offering something different from the average repetitive physiotherapy sheet. We knew people with Parkinson’s who wanted to exercise at the intensity research recommends, but didn’t know how.

We now have four Parkinson’s sessions a week and a community of Heroes whose motivation has shaped our unique offering. Playfulness is a huge part of the Neuro Heroes ethos, so our fitness section always has a theme - with requests from Heroes as wide-ranging as kung fu and carnival. One participant says “Anna has a great sense of humour and each session is filled with laughter and positivity” - building a sense of shared achievement. Making exercising genuinely fun makes the difference to people like Clare, who says “Time spent with Neuro Heroes is time well spent as it helps me to be fitter, happier and more productive”.

Outcomes and next steps:

Our virtual sessions attract participants from around the UK, and accessible sessions mean we can group participants to best meet their needs. Participants set six weekly goals and say “Neuro Heroes has made a huge difference to my physical fitness and mental wellbeing”. People have increased their one minute sit to stand scores by an average of 15 repetitions, and have consistently reduced the number of steps needed to turn, improving functional balance and reducing falls risk. We share our approach and reflections with specialist teams so the benefits can spread. Our Facebook group ensures regular contact

with our community and allows us to continue the valuable feedback loop that has enabled us to truly meet our participants’ varied needs.

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Using a person-centred approach in caring for a person with Parkinson’s and collaborative working with Parkinson’s UK in providing extra publicity for the charity.

Lisa Renton
Sunderland Royal Hospital, Sunderland, United Kingdom

Abstract

OBJECTIVE

In my role as a Parkinson’s Nurse Specialist I always ensure that I provide a person centred care approach to ensure individual care needs are continually met. My goal is to ensure that the care I provide helps empower people with Parkinson’s and their families/carers by being listened to, feeling understood and valued at all times.

INTERVENTION

Approximately 14 months ago I received a call from the wife of a gentleman who had recently been diagnosed with Parkinson’s under our Neurology services. Her husband was aware she was contacting us. The lady explained her husband was in his early forties and the Parkinson’s diagnosis had come as a shock to them both. She was very weepy and fearful for the future. We had a lengthy discussion in which I ensured she was fully supported and well informed as the families/carers of people with Parkinson’s also need to have a voice and be understood.

I contacted the gentleman and we had a lengthy chat regarding his diagnosis. Using a person centred approach I identified the gentleman was a very successful business owner and would be used to taking the lead in situations. I therefore felt it was imperative that he understood that he would be fully involved and supported in all decisions in regards to management of his Parkinson’s.

The gentleman explained that his outdoor digital advertising business was going from strength to strength and we discussed him becoming involved in raising awareness of Parkinson’s through his business. With his permission I contacted our Parkinson’s UK Area Manager and provided her with the gentleman’s contact details.

OUTCOMES

Parkinson’s UK and the gentleman have been successfully working collaboratively to raise awareness of Parkinson’s though outdoor digital advertising using billboards in which one was above the Tyne Tunnel. Parkinson’s UK and the gentleman have now posted their collaboration on social media and will continue to work together in raising awareness of Parkinson’s’.

Continued cycles of improvement rely on information such as outcomes from audits. I feel I have addressed two areas of improvement required in Neurology following the results of the 2019 Parkinson’s UK Audit – ‘**Care of people in work who have Parkinson’s’** and **Multidisciplinary team approach.**

I feel using the person centred approach to care has led to this gentleman feeling empowered, valued and listened to. In regards to his collaboration with Parkinson’s UK he explained “It feels good to help people in a similar situation to myself”.

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Change in Service Structure to support Invidualised Care and Patient Choice for People Living with Parkinsons and their Families

Dr. Sarah Williams, Dr. Ryan Mason, Diana Wilson, Claire Andrew
St Helens and Knowsley Teaching Hospitals NHS Trust, Prescot, United Kingdom

Abstract

Due to the pandemic our practice as a team altered significantly as we provided care for our patients. Our aim was to provide both remote and F2F care individually tailored to each patient. We wanted to build a more flexibly proactive and reactive service to address the varied needs of each person under our care. Many methods employed at this time have been adapted and remain an integral part of our ongoing practice with the aim of providing care tailored to individuals and their families.

Intervention

Methods employed include:

1. A choice of telephone, televideo or f2f review depending on patient clinical need and personal choice. Multimodal clinics allow us to switch between methods when required.

2. More regular contact than our previous 6/12 review to identify problems and issues promptly, an aim to reduce hospital admissions and ‘crises’

3. Access to consultants/ Specialist practitioner for patients and relatives for telephone/televideo support on a daily basis

4. Pathway links strengthened with already established community teams to intervene and avoid hospital admission i.e. urgent review by community frailty team with Parkinson’s support via telephone, televideo or domiciliary visit. Links with the crisis team and social services to intervene for cognitive and neuropsychiatric issues.

5. Urgent F2F Parkinson’s review depending on need and ease for the patient i.e. emergency clinic review, domiciliary visits, or the use of the ambulatory frailty unit for day admission for MDT review with Parkinson’s consultant leading

6. Support from community and hospital based palliative care teams for patients towards the end of life.

7. Regular contact with our local support groups, Parkinson’s UK, Carer support, and Local groups who provide Parkinson’s related activities i.e. St Helens walking group and Rock Steady Boxing in Widnes

OUTCOMES

We have managed to keep the service up to date with new referrals being seen within the 6 week recommended window and all patients having review within the last 6 months. We have received excellent verbal feedback from patients and relatives. We hope to follow up with patient satisfaction survey in the future.

Our overall aim, to provide rapid and thorough care for patients who live with Parkinson’s and their families, is an ongoing challenge. Every person is unique, and each individual has their own perception of what ‘quality of life’ means to them. We hope to be able to support them in their daily life and encourage activities that are meaningful to them.

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Final category: 3. Person-centred approach

6

Bridging the Gap between Health and Social care; Carers in the community who understand and support Parkinson’s.

Helen Morris[1], Danny Mills[2]
[1]Milcare Ltd, Rochdale, United Kingdom. [2]Milcare, Rochdale, United Kingdom

Award categories

3. Person-centred approach

Abstract

“Another day where the carers have turned up too early; I can’t blame them with so many people to see and not enough time, they do the best they can. But I also know how vital it is to get my medication at the right time, every time. When I don’t get my medication on time I suffer from motor symptoms and increased anxiety. I am left wondering if anyone will turn up some days. I know if I have regular people and the right times my anxiety will be reduced”

Too many times we hear this story; whilst the care from hospitals and clinicians has been commended, too many people are finding that a lack of understanding of Parkinson’s patients within social care is letting them down and causing them to experience symptoms unnecessarily. Clients want to live in their own homes and remain a part of the community. That is where Milcare was born. MILCARE – My Independent Life - Care. From an understanding of Parkinson’s, Danny Mills, Director, knew that things needed to change, that the level of care provided to Parkinson’s clients needed to improve and that the social aspects of caring for an individual with Parkinson’s needed an upgrade.

Milcare is a domiciliary care provider that specialises in Parkinson’s – each Personal Assistant is trained in Parkinson’s as part of their induction and has a strong understanding of how symptoms affect people differently and how best to help. Individual programmes of care are developed which address the needs of the whole person with an underpinning knowledge of the stages of Parkinson’s, the impact of symptoms, the Parkinson’s variants and treatment options. We have regular contact with local Parkinson’s nurses, attend appointments with our clients and we retain regular contact with local Parkinson’s groups. We are also part of the Excellence network.

Person centred care means each package of care is unique – taking the professional knowledge and understanding of a condition and utilising that knowledge to make someone’s support tailored to their individual wants and needs. What is important to one client may not be to the next. it is knowing that Doris, enjoying her morning walk with the dog, has different needs to Alan, who wants a game of dominoes on a Saturday: that Joyce, who enjoys nature programmes with Rington’s tea and a ginger biscuit, differs from George who only drinks coffee and likes to have breakfast in bed. Although all share the same diagnosis, this does not define who they are.

15

Ensuring people with Parkinson's obtain timely information and support at diagnosis with the background challenges of Covid19 and virtual working.

Lynne Osborne
Cornwall Partnership Foundation Trust, Cornwall, United Kingdom

Award categories

3. Person-centred approach

Abstract

The Community Parkinson's Service in Cornwall currently incorporates three Parkinson's Specialist Nurses (PSN's), two admin team members, a neuro physiotherapist and a Consultant Nurse in Parkinson's. We have been focusing on ensuring people with Parkinson's obtain timely information and support at diagnosis, with the background challenges of Covid 19 and virtual working.

This includes:

- Our Admin team contacting the new referrals to ascertain whether use of the NHS platform - Attend Anywhere is possible, otherwise a telephone review is offered. Based on service criteria a face to face appointment may be required.

.Mailing out the NMS Questionnaire, PDQ 39 / PDQ 8 and UPDRS part II for completion prior to the timely consultation with the PSN as part of a holistic assessment.

- Discussion of the referral benefits onto Parkinson's Connect. Cornwall is currently the highest referring area for newly diagnosed people with Parkinson's and their family members as part of the national Parkinson's UK project.

- The benefits of the Physical Self Management Programme (PSMP) are discussed and actively encouraged for the person with Parkinson's and family member to participate within. This quarterly neuro physio run programme with service user involvement has been developed through yearly service improvement funding from Parkinson's UK. The PSMP is based on evidence based practice and local patient focus groups regarding content / delivery. The importance of evidence based activity and exercise is the main focus to enable people with Parkinson's to start or remain active. Also to seek engagement with different exercise providers over the county going forwards. During Covid 19 this programme moved online and a mixed hybrid approach will be taken going forwards following evaluation. Cornwall has been part of a Devon initiative to train exercise providers prior to Covid 19 and enabling people attending the PSMG to be easily signposted to different forms of exercise. The aim going forwards is to bring group attendees back together to ascertain whether exercise has been embedded into daily life.

- Signposting onto the Living Well with Parkinson's online sessions

- Sending out a resource pack which has been developed by the local P UK Group in Cornwall for further information and support

- The development of newly developed survey which captures the feedback from the consultation as well as thoughts around future reviews. This is undertaken by telephone by our local Patient Experience Team.

- Encouraging the newly diagnosed person to contact our service via telephone / email going forwards rather than providing regular follow up care.

- Providing timely advice going forwards based on a developed RAG rating system to prioritise / triage care by the most effective face to face or virtual route.

24

Home Based Care for Parkinson’s

Camille Carroll[1,2], Emma Edwards[3], Sue Whipps[4], Martha Holley[5], Jane Rideout[6], Jemma Inches[1], Emma King[2], Sue Bentley[1], Georgie Gilbert[1], Joe Langley[7], Ursula Ankeny[7], Tracie North[2], Mathew Swabey[1]

[1]University Hospitals Plymouth, Plymouth, United Kingdom. [2]University of Plymouth, Plymouth, United Kingdom. [3]Livewell Southwest, Plymouth, United Kingdom. [4]PPI, Cornwall, United Kingdom. [5]PPI, Plymouth, United Kingdom. [6]PenPEN, Devon, United Kingdom. [7]Sheffield Hallam University, Sheffield, United Kingdom

Award categories

3. Person-centred approach

Abstract

Objective

To understand our service, we undertook a survey of people with Parkinson’s (PwP) and found that they often wait more than a year to be seen in clinic. We ran workshops with PwP and care partners (CPs) from all our community areas to identify what they would like from their Parkinson’s service. They told us: knowledge and understanding of Parkinson’s, involvement in care, and personalised care targeted to individual needs. This formed the basis of our new care pathway, Home Based Care (HBC), tailored to the needs of individual PwP, supporting their ability to manage their Parkinson’s, making sure they are seen by specialists when they need to be seen and using technology to be monitored at home.

Intervention

With PwP and CPs we have co-produced HBC, put it into action and evaluated how it worked. Our project management team included 2 PwP and a CP. We held 6 workshops with PwP and CP to develop HBC, including everything in the resource ‘pack’ (from the shape and size of the box to the colour of the font), and how the pathway would work. PwP helped us design the report that would allow them to understand the results from their remote monitoring with the Parkinson’s Kinetigraph watch and questionnaires.

The pathway started in Oct 2019. We continually asked for feedback to improve the pathway. We undertook telephone surveys, further workshops and recruited 9 PwP and 10 CPs to take part in interviews about their experience of HBC. By May 2021 we had 146 PwP on HBC. In Jan 2021 we evaluated the first 111 PwP on HBC.

Outcomes and Next Steps

Patient experience

After 6 months on HBC, PwP felt more involved in their care, listened to and treated as individuals; they had improved understanding of Parkinson’s and when to seek help. PwP and CPs felt more in control, empowered and supported. PwP not on HBC no longer had appointments delayed.

Symptoms and quality of life

All PwP motor and non-motor symptoms that we measured were improved after 6 months of HBC. Quality of life was maintained.

Improvements

We continue to improve and refine HBC based on PwP/CP feedback and evaluation. We are providing more support with self-management for those who need it. We are putting the questionnaires online for PwP and CP who prefer this. We are developing an app, which will replace some questionnaires. Our monthly HBC management meetings continue with our PwP and CP members, who also support sharing our project with PwP and Parkinson’s services across the NHS.

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Change in Service Structure to support Individualised Care and Patient Choice for People Living with Parkinson's and their Families

Dr. Sarah Williams, Dr. Ryan Mason, Diana Wilson, Claire Andrew
St Helens and Knowsley Teaching Hospitals NHS Trust, Prescot, United Kingdom

Award categories

3. Person-centred approach

Abstract

The St Helens and Knowsley Elderly Care Movement Disorders team were delighted to receive a nomination for the category of patient centred care.

We are a small team consisting of 2 Geriatricians, a Parkinson’s Specialist Practitioner and medical secretary who manage a caseload of approximately 650 patients, approximately 450 with a diagnosis of Parkinson’s disease, vascular Parkinsonism or a Parkinson’s syndrome.

Due to the pandemic our practice as a team altered significantly as we provided care and support for our patients and their families. As a result we were able to provide both remote and F2F care individually tailored to each patient. Many of the methods employed at this time have been adapted and remain an integral part of our ongoing practice with the aim of providing care tailored to individuals and their families.

Methods employed include:

1. A choice of telephone, televideo or f2f review depending on patient clinical need and personal choice. Multimodal clinics allow us to switch between methods when required.

2. More regular contact than our previous 6/12 review in order to identify problems and issues at an earlier point, an aim to reduce hospital admissions and ‘crises’ and support GPs.

3. Daily access to consultants and Specialist practitioner for patients and relatives for telephone/televideo support on a daily basis.

4. Pathway links strengthened with already established community teams to intervene and avoid hospital admission i.e. urgent review by community frailty team with Parkinson’s support via telephone, televideo or domiciliary visit. Close links with the crisis team and social services to intervene for cognitive and neuropsychiatric issues.

5. Urgent F2F Parkinson’s review via a number of methods depending on need and ease for the patient i.e. emergency clinic review, domiciliary visits, or the use of the ambulatory frailty unit for day admission to provide MDT review with Parkinson’s consultant leading.

6. Support from community and hospital based palliative care teams for patients towards the end of life.

7. Regular contact with our local support groups, Parkinson’s UK, Carer support, and Local groups who provide Parkinson’s related activities i.e. St Helens walking group and Rock Steady Boxing in Widnes.

Our overall aim is to provide rapid and thorough care for patients who live with Parkinson’s and their families. Every person is unique, and each individual has their own perception of what ‘quality of life’ means to them. We hope to be able to support them in their daily life and encourage activities that are meaningful to them.

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Reflections on supporting people with Parkinson’s.

DUNCAN GRAY
NHS HIGHLAND, INVERNESS, United Kingdom

Award categories

3. Person-centred approach

Abstract

Reflections on supporting people with Parkinson’s.

Having lived and worked in the Highlands of Scotland for a total of 25 years, I try to use my experience of the area in connecting with patients. In 2007 I recognized that we were taking many patients on a minimum of 130 mile round trips from the Lochaber area to Inverness. I set up our clinic based in Fort William on the principle of trying to achieve healthcare provision closer to home. Despite this I still have patients travelling by ferry and road to Fort William, and on looking back, some patients would still be travelling for more than 5 hours on a round trip for a review appointment, without our more locally delivered service. It goes without saying that this amount of travel can be exhausting for some patients, and will not improve attendance at distant services. Along with this there is now the clear recognition of all of our carbon footprints, and a positive benefit in reduced CO2 emissions. The medical team I am part of are particularly aware of minimizing patient travel times, with multiple locations for peripheral clinics in place.

From taking time to understand how a diagnosis is achieved and how other issues of health impact on individuals’ lifestyle I am keen to focus on the benefits of patients maintaining a focus on general well being. In supporting people with Parkinson’s we recognize our colleagues in other specialties and in other aspects of healthcare who endeavour to provide the best care for our patients. Sharon Sutherland is our Parkinson’s Nurse Specialist who works with clinicians across the whole of NHS Highland, and I think that she and I usually have similar thought processes on managing patients’ problems.

Another of the critical issues is untangling the complex relationship between medication, routine non-Parkinson’s medical issues along with the other health issues associated with Parkinson’s. I focus on understanding an individual and their past, their priorities and their situation to help to provide the tailored management people with a complicated condition such as Parkinson’s requires. I aim to maintain a positive relationship with patients, along with for realistic discussions on the pros and cons of medical treatments.

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Bringing PD Warrior - Bristol, UK into homes across the world to provide exercise support and guidance to people living with Parkinson's

Alistair Macfarlane[1], Kev Fry[2]
[1]PD Warrior - Bristol, UK, Bristol, United Kingdom. [2]PD Warriror - Bristol, UK, Bristol, United Kingdom

Award categories

3. Person-centred approach

Abstract

Objectives: Answering the need for people living with Parkinson’s to fair access to exercise and continued support during the covid-19 pandemic.

Intervention: When launching PD Warrior in Bristol in 2018 one the first objectives was to provide affordable access to Parkinson’s specific exercise of an established and successful programme. Working with Parkinson’s UK, North Bristol NHS and Everyone Active leisure centres we were able to provide courses and classes at local public facilities and away from private physiotherapy clinics – the only location in the UK to do so. Locations chosen consider travel, accessibility and cost.

When the global pandemic hit we were quick to join the online revolution so launched 3 online classes per week. The aim was not only to provide regular exercise but to keep people socially engaged, supported and motivated. When developing the classes we asked participants what they wanted and ensured the exercises were suitable to be done at home safely and with a lot of fun, whist still achieving the required effort level. The participants are not just people living with Parkinson’s who logged into a class but they became a community, supportive friends and Warriors! The WhatsApp group that we set up provides 7 days a week support.

We added a weekly recording of sessions that people could view and follow at a time more convenient to them and we also offered 1:1 sessions for those living in different time zones. This meant nobody was going to miss out on access to supervised PD Warrior exercises.

The classes introduced new exercises and are fully adaptable for anyone with balance problems or needing seated activity. We considered the content required, the length of the class and the time of day which would have the most impact of management of Parkinson’s. We committed to the class with passion and dedication wherever we were in the country even running them on family holidays, the middle of a field or at a motorway service station!

We invite feedback to keep classes fresh and what the participants want and need and we can tailor exercises for individuals depending on their focus.

Outcomes and next steps: Our online classes were so successful that we have reached an audience far greater than the Bristol area with participants coming from not only across the UK but from South Africa and Australia. This has shown us that PD Warrior can be just as successful online as it is face to face so we will continue, and even grow, our online presence, which is affordable and convenient to access.

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Multidisciplinary Patient Centred Care During Covid

James Shaw, Linda Patterson
Nhs Tayside, Dundee, United Kingdom

Award categories

3. Person-centred approach

Abstract

Objective

To maintain our multidisciplinary patient centred approach during covid times.

Background

In Angus, we have a Locality based MDT service across the 4 localities within Angus Health and Social Care Partnership in Scotland. We have one Parkinson’s Specialist Nurse (PNS) and have been refining our service over the last 15 years. We recognise that our patients needs vary and operate needs based service. We encourage our patients to be ‘in charge’ of their long term condition, to offer support and not overly medicalise it. Our PNS is central to this offering phone advice, phone Parkinsons Nurse face to face clinic and arranging medical reviews. The backbone of our service is the MDT annual review clinic when the patient rotates around members of the MDT (physio, PNS, OT and doctor) including a coffee break with other patients. Then we have a meeting to discuss the patients and create a plan which is then communicated to the patient and their GP in writing.

Intervention

With covid, parts of our usual service eg patients being in charge of their long term condition, phone advice and face to face reviews if needed, have worked well, and have used ‘Near Me’ video consultation with some success. We ensured our PDNS was not redeployed as she was key to providing care for patients with parkinsonism. We have strived to keep and patient centred focus but the annual review clinic was not possible due to infection control risks so we scaled it down to PNS and Doctor at their usual annual review time. At first it was a dual phone review but as covid restrictions eased we went back to face to face annual reviews but limited to doctor and PNS. Throughout this other members of the MDT (Physio and OT) were kept including to email prior to the annual review and offered information that was known to them from other interactions with the service, and the OT team designed a questionnaire to identify needs. When able they were able to join us afterwards to discuss the patients. As expected, we could only have limited patients in clinic and their was no opportunity to have the patient group aspect of the clinic.

Outcome and next steps

Our patients were grateful for their continued care/ support through the pandemic and the efforts we went to to adapt. One of out patients nominated us for this award. We are very proud of how we continued to support our patients as we had a good service set up prior to the pandemic which saw us through the pandemic.

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Person centred approach

Kevin Fry
PD Worrior, Bristol, United Kingdom

Award categories

3. Person-centred approach

Abstract

My name is Kevin Fry, I am the other half of the PD Warrior training team in Bristol.

It has been a very difficult year and a half for everyone, but for people who depend on the classes for physical support and social activity it has been exceptionally difficult.

As a team we continued to offer support to our clients and friends with Parkinson’s, by continuing classes online.

This gave everyone a fresh prospective and kept them and us positive, during a difficult period.

One of my clients was based in Australia so taking part in the group classes was not possible for her.

Pat asked if I could arrange individual sessions in the early mornings due to the time difference.

Although she could have had recorded sessions she wanted to be encouraged to keep going and found that the recorded sessions were not enough to encourage her.

I was happy to do this and designed a programme tailored to her needs. Pat was very keen on the shadow boxing aspect included in her programme. This was very effective in helping with her balance, she can now incorporate some weights into her programme.

Originally the sessions were once weekly, but Pat was so pleased with her progress she increased this to three times a week.

The greatest satisfaction that I get from training individuals and groups is to see the progress clients make, and to watch their confidence grow when they realise that the exercises can allow them more freedom of movement and allow them to do things, they thought they wouldn’t be able to.

In Pats case, her consultant was extremely pleased with the progress and so was pat.

She continues to work with me, and I am very pleased to see how far she has come through her hard work and determination.

I am very excited that we have just started our live group sessions in Bristol, it has been so good to get people together again with the same goals