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

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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].

Learning shared

- Presenting how we worked with commissioners and colleagues to develop a truly integrated MDT-led pathway to Parkinson's UK Excellence Network Yorkshire and at an educational national webinar
- Publish the pathway as a peer-reviewed article in a journal[1]
- Multiple local teaching sessions to support those caring for people with Parkinson's including GPs, Dietetics, Speech & Language Team and local hospital teams.
- Sharing learning with the Parkinson's excellence network's Patient centred MDT-led care steering group
- Held education sessions for patients and their carers
- Contributing to an educational book on MDT-led care for people with Parkinson's
- Sharing learning including software template ideas with other services

The Integrated Team

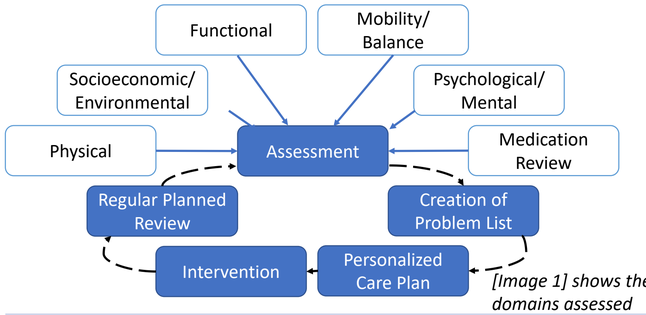
The challenge of integrating healthcare professionals from multiple different employers was met by creating a "team culture" adhering to the self-developed moto of "be kind, be helpful, be patient centered".

The team consists of:

MDT Coordinator
Neuro-physiotherapist
Occupational Therapist
Therapy Assistant
Frailty Community Psychiatry Nurse works with team case-by-case
Pharmacy Technician
Parkinson's Nurse Specialist
Clinical Support Worker
Consultant Physician

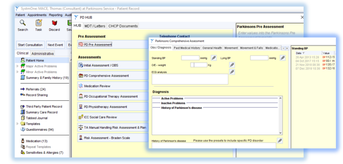
The somewhat novel role of the MDT coordinator role in Parkinson's acts as a single point of access for patients and carers seeking assistance from the Hub. They direct queries to the appropriate allied healthcare professional and arrange appointments, referrals and call backs. Efficiency savings are made of clinical healthcare professional time and patients are kept informed of what and when to expect.
Many members do not work full time within the team and have a range of experience in caring for people with Parkinson's. All are supported in developing this experience through monthly teaching and support in attendance of external continuous professional development opportunities.

Building resilience using Comprehensive Parkinson's Assessments



[Image 1] shows the domains assessed

Common onward referrals
Speech & Language Team
Dietician
Specialist consultants
Diagnostics (e.g. scans)
Talking therapies
Tissue Viability
District Nurses
Bladder & Bowel
Palliative Care/Dove House
Carer Support
Parkinson's UK

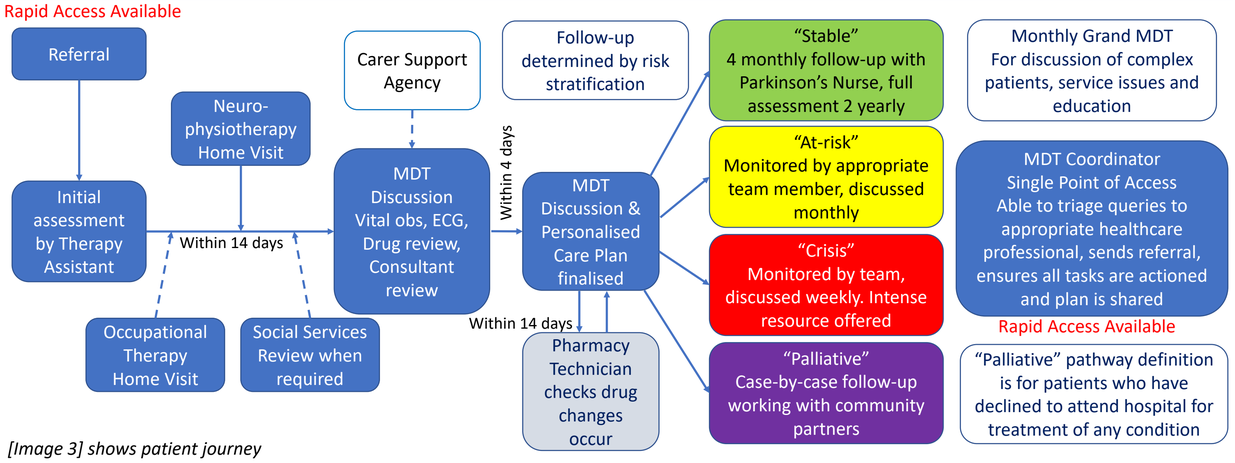


[Image 2] is a screenshot of the bespoke template for the assessment developed for the Hub and accessible by community colleagues on SystmOne

"Frailty" is a vulnerability of a person to not return to their normal functioning baseline after a stressor event. It has been demonstrated that comprehensive geriatric assessment can reduce mortality, improve function, decrease level of dependency and possibly reverse frailty[2]. It does this by building resilience. People living with Parkinson's need to be assessed holistically with solutions to difficulties in any domain, hence the need for a multidisciplinary approach and a strong network of community colleagues for onward referral. By making each domain as strong as possible, for instance ensuring the environment is safe even "on a bad day" and addressing any carer stress or burnout, this builds resilience into the person living with Parkinson's and their home environment. When a stressor event occurs, such as infection or bereavement, the person relies on their other domains to be as strong as possible which may avoid a severe decompensation and giving the person the best opportunity to come back to the quality of life they currently enjoy. We have developed a bespoke template on SystmOne on which all findings are recorded and the personalized care plan is stored. This is viewable by the GP and involved community colleagues. The intervention occurs and the patient is regularly reviewed with issues fed back into the twice weekly MDT to ensure no complications or side effects have occurred. After 2 years, the cycle starts again.

Patient Journey

Rapid Access Available



[Image 3] shows patient journey

Patient referral for people living with moderate to severe frailty using the Clinical Frailty Scale[3] or symptoms not responding to traditional care. Sources of referral are predominantly from the local Parkinson's Specialist Nursing team but also include the local Emergency Department and hospital wards, community allied healthcare professionals (e.g. Speech and language therapists), rehabilitation settings and care homes.

Patients can be seen rapidly (within 3-7 working days) if required. Initially, they are seen by the therapy assistant who assesses their environment, function, care situation and a performs a clinical questionnaire on non-motor symptoms. A neuro-physiotherapist assesses the patient's function using tools including the Lindop Parkinson's Physiotherapy Assessment Scale and a rehabilitation programme prescribed. An occupational therapy review us usually required with assessment following the Royal College of Occupational Therapy Parkinson's guidelines. Within 14 days, the patient is welcomed to the Jean Bishop Integrated Care Centre (a purpose-built center for patients living with frailty). Here, they will have vital observations and an ECG performed. A pharmacy technician will assess for medication taking difficulties such as remembering, dexterity and swallow. Drug interactions and not-required medications will be highlighted. An hour-long review with the consultant physician ensues based around issues found during the initial assessment. The patient is offered complementary snacks and beverages throughout their stay. Within 4 days the MDT will discuss findings and a personalized plan will be finalized and shared with the GP electronically and the patient. All medication change recommendations to the GP are followed-up by the pharmacy technician within 2 weeks to ensure they have been actioned and to troubleshoot any difficulties, meaning patients do not have to contact the GP themselves. The MDT coordinator ensures all tasks are completed by those responsible and highlight any difficulties during MDT meetings. Any requirement for cognitive and mood formal assessment occurs in the patient's own home by the therapy assistant. Patients living in a care home or who cannot attend the center will be assessed in their own environment by all team members.

Patients are risk-stratified: "stable", "at-risk", "crisis" or "palliative". Those felt to be at risk of hospital or care home admission are seen rapidly with resource concentrated on stabilizing the current situation and support is given to their care-givers. Usual follow-up is 4 monthly with capacity of rapid access appointments when required. After 2 years, another comprehensive assessment will occur.

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.

Feedback

[Image 4] Word cloud from the Family & Friends test

Feedback reflects the friendly and helpful attitude of the team.
Other feedback has included:

- "For the first time in years, someone listened to our problems"
- "They make my husband and myself feel very important"
- "They do everything they say they will"
- "The advice I got… was like a light at the end of the tunnel"
- "An extremely informative discussion"
- "Mum feels safe, she feels like a person… not just a number"

Quantitative data has been difficult to assess due to variables including hospital admissions and deterioration secondary to the COVID pandemic

References

(1) Mace T, Peel C. ACNR 2020;19(4):38-41
(2) Stuck AE et al. JAMA 2002;287(8):1022-8.
(3) Rockwood Clinical Frailty Scale. Canadian Study on Health & Ageing, revised 2018

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