

Parkinson's Hub: An integrated pathway for people with Parkinson's and frailty



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An innovative, integrated and multi-disciplinary-led community pathway for people with Parkinson's and related disorders with co-existing frailty has been commissioned by Hull clinical commissioning group (CCG). This is part of the CCG's strategy to address frailty within its local population, working both proactively and reactively to support patients to live well and reduce strain on the local hospital.

Kingston-Upon-Hull is a city within Yorkshire in the United Kingdom and has an estimated population of approximately 260,000.¹ It is in the 5% most deprived local authorities.² With a move towards integrated care, there have been many challenges; existing systems are not designed for this new way of working. These difficulties have been overcome by enthusiastic cross-working between the Hull CCG, Hull University Teaching Hospitals NHS Trust, City Health Care Partnership CIC and Hull Local Authority with assistance from the voluntary sector including Parkinson's UK.

Background

The NHS Long Term Plan (2019) encourages a move to a more holistic, multi-disciplinary team (MDT)-led integrated care in the community, closer to where patients live.³ Furthermore, it has placed a focus on frailty. Clegg et al defines frailty as:

'a state of vulnerability to poor resolution of homeostasis after a stressor event and is a consequence of cumulative decline in many physiological systems during a lifetime'.⁴

Non-frail patients can usually expect to return to their baseline once they recover from the stressor. However, those who are frail or vulnerable to frailty are at risk of not achieving this and thus have an increased risk of developing a higher level of dependence, disability or death.⁵

The association between Parkinson's and frailty is interesting in that it leaves the body's physiological systems and mind vulnerable to stressors and is highly associated with conditions such as falls, cognitive dysfunction, immobility, incontinence and susceptibility to side effects of medications, often seen as 'frailty syndromes'.⁶

Parkinson's may directly cause or co-exist and compound frailty. The Rockwood Clinical Frailty Scale (CFS) is a useful way of classifying non-frail and frail states, viewing frailty as a spectrum of a physiological state.⁷ However, the effect of more advanced Parkinson's and the variability of living with daily "on"

and "off" states and response to treatment is less well understood. Kempster describes that although younger patients usually have a more prolonged maintenance phase, once events such as visual hallucinations, falls and cognitive dysfunction occur, the prognosis is similar regardless of age.⁸ Parkinson's requires a holistic approach and sensitivity to the patient's own goals throughout the disease especially when multiple frailty syndromes affect their quality of life. Hence, the referral criteria into the service is loose with no exclusion criteria, although a CFS score of 6 (moderate) onwards is used as guidance for those living with multiple 'frailty syndromes'. There are no age restrictions.

Until recently, the existing Parkinson's service followed a common model of diagnosis by a movement disorder Consultant and routine follow-up with a Parkinson's disease Specialist Nurse, with referral back to the specialist when required with no MDT meeting.

A push by Hull CCG towards providing holistic care for patients living with frailty in the community has resulted in the opening of the Jean Bishop Integrated Care Centre. Comprehensive Geriatrics Assessments (CGAs) are performed on patients invited for review, after screening using the electronic frailty index algorithm. Briefly, a CGA is a diagnostic process performed by members of the multidisciplinary team, assessing: physical and mental health, socioeconomic, environmental, mobility and functional factors and a medication review, culminating in a personalised plan of interventions to address the issues raised.

As an in-patient tool, CGAs have been shown to demonstrate a decrease in those admitted to nursing homes compared to routine medical care.⁹ In the outpatient setting, outcomes are less well understood but one study found it "may delay the progression of frailty and may contribute to the improvement of frail patients in older persons with multi-morbidity".¹⁰

Aims

The service aims are identified in Table 1; these were created following a focus group of people with Parkinson's and their carers and through the specialist healthcare team.

A framework was developed: the 'Comprehensive Parkinson's Assessment' (CPA). This is very closely influenced by and aligned with CGA which is advocated by the British Geriatric Society¹¹ and augmented by Parkinson's specific questions. It takes into account themes from the NHS RightCare Progressive Neurological Conditions Toolkit,¹² the Non-motor Symptoms Questionnaire¹³ and

Table 1: Aims of the Parkinson's Hub and of any MDT-led community frailty service as identified by patient and healthcare communities

Identified by people with Parkinson's and their carers	Identified by the healthcare team, CGA, and Parkinsons UK National Audit
More information / education about their disease	Improve quality of life
Quicker access to healthcare professionals with an interest in Parkinson's	Responsive service
Expertise from their healthcare professionals	Reduction in non-elective hospital admissions
Quicker medication changes	Reduction in falls and fragility fractures
	Reduction in pain
	Rationalising of polypharmacy
	Advanced care planning
	Reduction in permanent care home admission Improvement in respecting a patient's preferred place of death
	Improved links with mental health services

Table 2: The core themes included in Comprehensive Parkinson's Assessments

General Health	Cognition, mood, neuropsychiatric, sleep and social services (ICD) assessments
Frailty, Hoehn & Yahr and observations	Continence and bowel function
Nutrition, swallowing, speech issues and oral health	Function and pain
Movement, motor-symptoms and falls	Sensory function
Bone health	Environmental and carer requirements
Medication and polypharmacy review	Future care plans and wishes

Table 3: The personnel comprising the new Parkinson's Hub team

Staff involved	Their role / further information
Consultant Geriatrician with an interest in movement disorders	2 morning clinics (2 x 4 hours) per week to perform the clinical aspect of Parkinson's assessments, routine and rapid-access follow-ups and lead the MDT meeting. Acts as Clinical Lead for the service.
Parkinson's disease Nurse Specialist (1 whole time equivalent)	Currently working a part-time 27.5 hours per week. Work is a mixture of clinics, home visits, care home work, MDTs and networking with other agencies.
Consultant Neurologist	Offer second opinion, education and shared decision making for complex cases.
Band 6 Physiotherapist	On an annual rotational basis linked with other rotations including 'frailty'. Supervised by a Band 7 Neuro-Physiotherapist with a special interest in Parkinson's.
Band 6 Occupational Therapist	2 days per week with 3 days working within the closely aligned "core frailty" team. Support to develop a specialist Parkinson's interest is available.
Band 4 Therapy Assistant	Supports both the physiotherapy and Occupational Therapy team.
Full-time MDT Coordinator role	Split between 2 colleagues, to ensure cross-cover. They are the patient's single point of access to the service and maintain the comfort of the patient alongside the smooth running of the service. They complete administrative tasks and ensure all tasks are completed from the patient's individualised plan.
Pharmacy Technician	2 days per week to assess medication concordance and dexterity whilst suggesting possible improvements in prescribing and ensuring medication changes occur in a timely fashion.

the Parkinson's UK National Audit.¹⁴

The core themes included can be found in Table 2. The NHS RightCare Progressive Neurological Conditions Toolkit is influential in its promotion of MDT work, signposting of Parkinson's UK local advisors and the use of care coordinators. The Parkinson's UK National Audit prompts questions that are Parkinson's specific, e.g. regarding hypersalivation and psychosis.

Integration and Personnel

A team, working seamlessly as an extension of the current team at Hull University Teaching Hospitals, and comprising current and new healthcare professionals has been formed to support the new service. The team is formed of colleagues (Table 3) with various employers working within a structure provided by the aforementioned agencies, all working to a common goal: to provide great community-based care. Hull CCG has significantly increased the resource into the team.

In addition to the core team, there is input from pharmacy technicians, a clinical support worker, carer support agency workers and

Parkinson's UK (when capacity allows). Throughout the assessment, there is seamless working and data sharing with the local authority's social services team and Dove House Hospice (where applicable).

The Parkinson's Hub service

The service flows in three parts: a referral, an assessment in two parts, and a follow-up. This can be seen in Figures 1-3.

At the mini-MDT meeting following the clinic, each patient is given a stability classification to determine whether they are 'Stable', 'At-risk', 'Pre-crisis/Crisis' (defined as likely to result in hospital or 24 hour care admission) or 'Palliative'. All individualised plans will be sent by the next working day to the patient, their General Practitioner (GP) and the local hospital. Those deemed as Pre-crisis/Crisis will be discussed in the monthly Grand MDT which has attendance by the usual MDT, with additional representation from social services, care home staff, and any other parties involved in the patient's care.

There is close collaboration with the local care home frailty team. The palliative care

pathway has been strengthened for those who have declined further hospital admissions and have chosen to be cared for within the community only and supported through the dying process. They are referred to the district nursing team who provide the majority of community palliative care. Multiple patients attend the Dove House day hospice service who also support the patient if symptoms become difficult to manage. Data is shared between the services and communication is open both ways to obtain clinical advice for all the teams mentioned above.

Information technology and data sharing

Locally, 'SystemOne' is the main software used amongst GP practices, although some practices do use 'EMIS'. A dataset for the group of patients has been established. Templates based on the CPA to frame each patient contact have been created on SystemOne with read codes used wherever possible to aid data sharing and analysis.

As the service spans multiple agencies, a thorough consent process for data sharing has been agreed. After verbal, then written patient

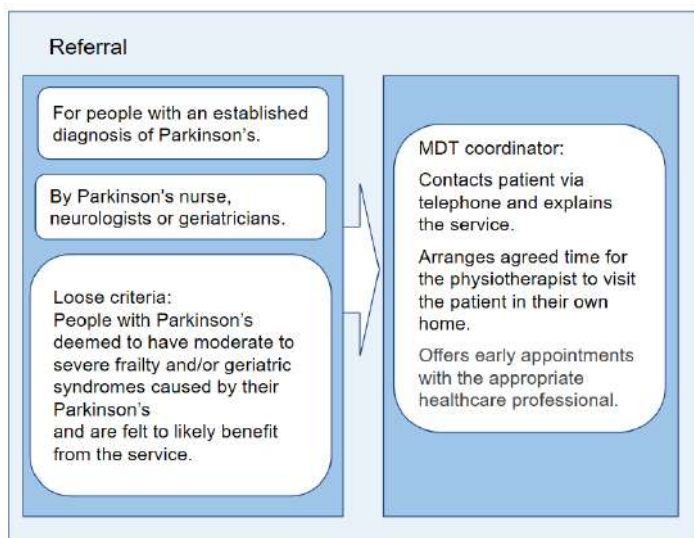


Figure 1: The Parkinson's Hub service flow: referral.

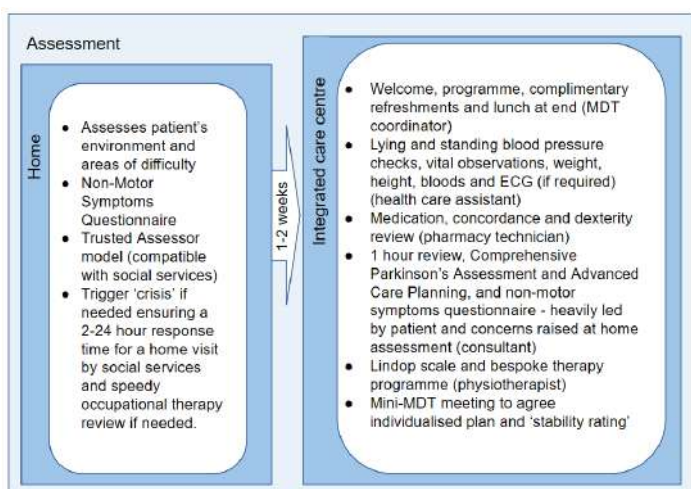


Figure 2: The Parkinson's Hub service flow: assessment
References within Figure 2: Non-motor Symptoms questionnaire [13], Lindop Scale [15]. A diagrammatic model of the service can be found in Appendix 1.

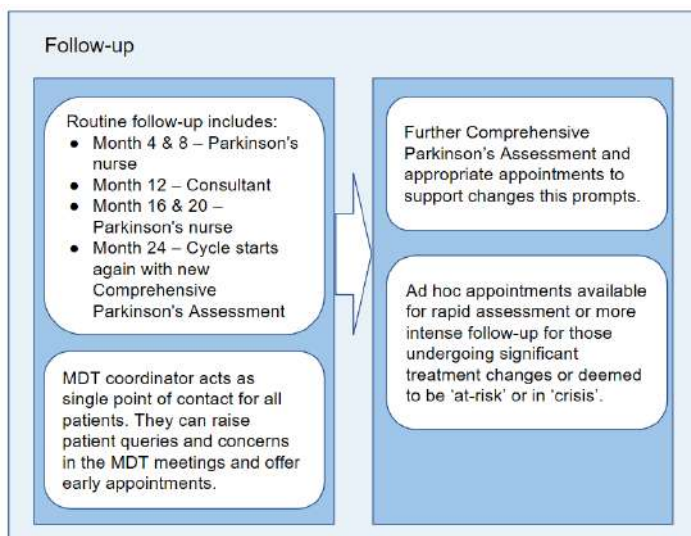


Figure 3: The Parkinson's Hub service flow: follow-up

consent, the Parkinson's Hub requests patient records from the GP and can share these within the services including social services. Further, the Individualised Patient Plan can be shared with the patient, the patient's GP and the local hospital.

Evaluation and next steps

During the Parkinson's Hub induction workshop for the whole team, a service culture was identified which was: "Be Kind, Be Helpful, Be Patient-Centred" and early feedback suggests this culture is tenable. The service welcomed its first patient on 1st November 2019, following a home assessment on the 29th October 2019. The number of patients has been kept low initially so that learning can take place and the team can become familiar with new systems.

Using the 'Friends and Family' test, so far 100% of patients have stated they are "extremely likely" to recommend the service (15 completed surveys). Most individualised plans have between 8 and 20 outcomes and timely follow-up on these changes has become imperative. It is currently too early to assess what objective impact they have but there is an ambition to publish outcomes of the service in due course.

Moving forward, there are many improvements and additions to the service to be developed as outlined in Table 4.

Conclusion

The Parkinson's Hub service remains in its infancy but is well placed to deliver on its ambition to potentially slow the progression of frailty and lessen the deleterious effect on people with Parkinson's and their carer's quality of life that frailty syndromes cause.

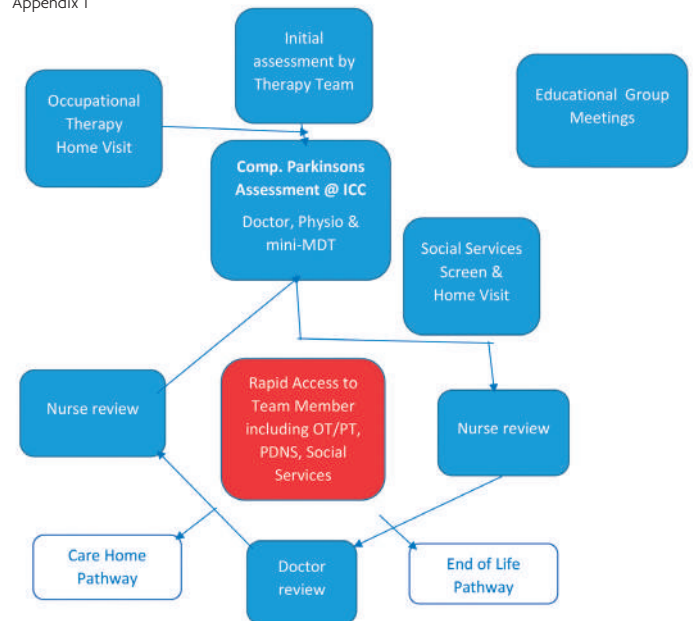
We hope that by sharing the learning of this early work we will encourage colleagues in other areas and open discussion on working in an integrated fashion across organisations and services, ensuring that people living with Parkinson's and their carers experience joined up and timely care.

Table 4: next steps and forward planning for the service	
Ambitions for the Parkinson's Hub service	Rationale for that ambition
Evaluate and modify the service as required	Ensure the service is always optimised to best support those it serves
Improve links with Mental Health services	Ensure support for the with Parkinson's who develop psychosis, Parkinson's dementia or more severe forms of depression and apathy associated with the condition
Work with colleagues to develop research links with local centres	Enable more variety, sample size and type, and a broader range of research in Parkinson's to be made possible
Support an Occupational Therapist to develop an interest in Parkinson's	To have a permanent Occupational Therapist within the hub to support motor symptom management e.g. gait, freezing, overall mobility, etc
Continue building links with Dove House Hospice and District Nurses	Enabling support of people in their homes or within palliative settings as and when this may be required
Rapid access Speech & Language Therapy Team	To offer strategies to manage hypophonia, communication issues and swallow dysfunction (to reduce the risk of aspiration pneumonia)
Develop an outpatient Clozapine service	Clozapine has been found most effective for treating psychosis in people with Parkinson's; having a designated clinic to treat this symptom would expand the service use
Share learning from the development and delivery of the Parkinson's Hub	Sharing positive practice to inform other services can enable service improvements in other areas of the country

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Appendix 1



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Hereditary Spastic Paraplegia (HSP) Support Group

The Hereditary Spastic Paraplegia (HSP) Support Group is a small UK charity run by volunteers. It aims to provide support to those with HSP, their families and their carers. The group creates a friendly community allowing its members to feel less isolated and share their stories with each other. The charity regularly runs local meetings across the country, with a larger AGM in July. They publish a newsletter two to three times a year and keep their website up to date (<https://hspgroup.org/>). They also have a private Facebook page, which can be accessed (<https://www.facebook.com/hspgroup.org/>), where members can discuss anything they want. Members can apply for funding for mobility aids or other equipment to improve their quality of life. Members fundraise and the charity are proud of their annual Potato Pants Festival (<http://potatopants-festival.co.uk/>). They also provide research grants to promote HSP research, part funding two UK PhDs this year. The charity are striving to make themselves better known to relevant healthcare professionals, so that patients with HSP can be directed to them for support. They are there for the whole journey, not just the diagnosis, and would appreciate if healthcare professionals can: 1. Advertise the group to patients/carers with HSP under your care and your colleagues. 2. Become honorary members of the group. 3. Help to identify guest speakers for their meetings. 4. Apply for small research grants which can be provided annually.

Please contact: mitesh.patel16@nhs.net or chair@hspgroup.org if you would like more information or leaflets.



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