

Impact case study (REF3)

Institution: University of Northumbria at Newcastle		
Unit of Assessment: 3 (Allied Health Professions, Dentistry, Nursing and Pharmacy)		
Title of case study: Caring for carers of people with Parkinson's Disease through improved policy, practice, and experiences		
Period when the underpinning research was undertaken: 2014 – 2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Annette Hand	Associate Professor	01/09/2014 – Present
Period when the claimed impact occurred: 2017 – December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>People with Parkinson's (PwP) experience a range of disabling symptoms that fluctuate and evolve over time. Research by Dr Annette Hand at Northumbria University has shown how informal carers of PwP continuously adapt by adopting new and challenging roles, often at a cost to their own health. This can result in PwP moving into hospital or formal care earlier than if their carers had been better supported. Hand's research has been used by the charity Parkinson's UK in their policy engagement (including recommendations for a NICE toolkit to support neurological conditions) and led to the new Parkinson's Connect support service for PwP and their carers, which is rolling out across the UK. A new Parkinson's recording template on the NHS electronic patient record system SystemOne has also been created, so that care of PwP explicitly includes their carers. As a result of these innovations, carers feel more supported, have better access to services and are able to care for PwP in the community for longer.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>Parkinson's Disease (PD) is the second most common neurodegenerative condition in the UK, with 18,000 people being newly diagnosed each year in the UK and a prevalence predicted to reach over 168,000 by 2025. People with Parkinson's (PwP) can experience a range of distressing and disabling symptoms that progress and fluctuate.</p> <p>While the symptoms and treatment of PD are becoming better understood, research led by Dr Annette Hand at Northumbria was the first to focus on how symptoms of PwP are being managed at home, including the roles and characteristics of informal carers. Supported by colleagues from Northumbria Healthcare NHS Foundation Trust, the research established that 80% of PwP who live at home do so with informal care support, with the average age of caregivers being 71 years old [R1, R2]. This informal care saves around GBP70,000 per person from health and social care budgets, but can have significant detrimental effects and strain on the carers – particularly as they are ageing themselves – including on their mental health [R2].</p> <p>The Northumbria Care Needs Project began in 2014, a collaboration between Hand and Parkinson's Disease Northumbria (a nationally recognised NHS specialist Parkinson's service). This project investigated the care needs of PwP at home and in care home settings, and the impact of the condition on both the PwP and their carers. This mixed methods study involved 164 PwP, including 115 patient-carer partnerships with moderate to advanced PD and 49 PwP without an informal carer, all still living at home. A range of validated quantitative outcomes were measured at the beginning and again two years later, including: demographics, disease status, frailty score, quality of sleep, quality of life, and mental health [R1].</p>		

An additional 114 variables, based on a stress appraisal model, were measured for carers, including: coping strategies, personality types, roles and activities undertaken, the extent to which formal care mechanisms were in place, and a relationship assessment [R2]. In-depth interviews with ten carers of PwP who had gone into care home placement during the study period built on the quantitative data to further understand what led to the need for referral. In care homes, PD symptoms can be difficult to manage effectively because of the challenges of balancing effective medication with drug side effects [R3] and the fact that care home staff sometimes fail to recognise the fluctuating nature of PD, which can lead to missed care needs [R4]. This results in PwP experiencing worse outcomes and higher mortality in care homes. Maintaining a healthier home environment for both PwP and their carers, for longer, is therefore vital. For the first time, factors in care journeys that could predict care home placement were characterised [R1, R4-R6].

The research highlighted that PwP without a carer access formal care more quickly and comprehensively than people with an informal carer [R1]. PwP-carer partnerships adopt adaptive *ad hoc* strategies at home, with the caring role developing slowly over time. Carers learn to manage complex fluctuating motor symptoms, psychological issues, and the pragmatic aspects of caring at home, typically with very little professional support. This puts strain on both the carers themselves and their relationship with the PwP. This strain often goes unnoticed by formal services until the partnership has reached crisis point, necessitating admission to hospital or care home placement [R5, R6]. This research therefore highlighted the essential need for formal services to interact with, and support, informal carers much earlier in their care journeys.

This research [R1-R6] was funded by Parkinson's UK [G1] and was the first study in the UK to have explored holistically the care needs of PwP [R1], and the role and characteristics of informal carers [R2]. It also examined the relationship between hospital admissions and care home placement [R5]. It identified that increased social support could reduce the risk of hospital admission for PwP [R4] and established carer strain as an important factor behind care home admission [R6].

3. References to the research (indicative maximum of six references)

R1. Annette Hand, Oates, L. L.*, Gray, W. K.*, and Walker, R. W.* (2018) 'Understanding the care needs and profile of people living at home with moderate to advanced stage Parkinson disease' *Journal of geriatric psychiatry and neurology* **31** (5): 237-247

<https://doi.org/10.1177/0891988718788680>

R2. Annette Hand, Oates, L. L., Gray, W. K., and Walker, R. W. (2019) 'The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease' *Aging & mental health* **23** (3): 337-344 <https://doi.org/10.1080/13607863.2017.1421612>

R3. Annette Hand, Gray, W. K., Oates, L. L., Woolford, M.**, Todd, A.**, Bale, E.**, Jones, C.*, Wood, B. H.*, and Walker, R. W. (2016) 'Medication use in people with late stage Parkinson's disease and parkinsonism living at home and in institutional care in North-East England: A balance of symptoms and side-effects?' *Parkinsonism & Related Disorders* **32**: 120-123

<https://doi.org/10.1016/j.parkreldis.2016.09.001>

R4. Oates L.L., Annette Hand, Dismore L*, Gray, W. K., and Walker, R.W. (2019) 'Improving care home life for people with Parkinson's' *Nursing and Residential Care* **21** (6): 309-316

<https://doi.org/10.12968/nrec.2019.21.6.309>

R5. Klaptoz, J.*, Gray, W. K., Marwood, S.**, Agarwal, M.**, Ziegler, J.**, Webb, Z.**, **Annette Hand**, and Walker, R. W. (2019) 'The pattern of hospital admissions prior to care home placement in people with Parkinson's disease: evidence of a period of crisis for patients and carers' *Journal of Aging and Health* **31** (9): 1616-1630

<https://doi.org/10.1177/0898264318786125>

R6. Brock, P. *, Gray, W. K., **Annette Hand**, Oates L. L., and Walker R. W. (2018) 'Improving and integrating care for Parkinson's disease' *Nursing and Residential Care* **20** (12): 615-620 <https://doi.org/10.12968/nrec.2018.20.12.615>

*Northumbria Healthcare NHS Foundation Trust **Newcastle University

Research funding

G1. Parkinson's UK, 2014-2016, GBP34,990.53 (G1310)

4. Details of the impact (indicative maximum 750 words)

Hand, a clinical academic with 23 years of experience in the field of PD and strong stakeholder connections, formed a key bridge between Northumbria University and practice in PD, both locally and nationally. Her position as a clinical academic was critical for delivering impact from the research. As a result of a lack of research into the caring needs of PwP, the support services available to carers were limited and inconsistent. The research undertaken at Northumbria had an impact on service design, practice, and policy, with subsequent improvements for PwP and their carers alike.

4.1 Impact on Parkinson's UK's support services

Parkinson's UK is the biggest charitable organisation focused on PD and its treatment in the UK, covering all 300 NHS specialist Parkinson's services nationally. In 2018, based on her research expertise, Hand was appointed as the nurse lead on the Parkinson's UK Excellence Network, which develops and shares best practice across the UK, to improve the care for PwP and their families. Hand has also served on Parkinson's UK's Excellence Network Underserved Group since 2015, a taskforce created to provide a strategic, nationwide approach for those who miss out on support.

Hand's research underpinned the redesign of Parkinson's UK's support services, which has led to the introduction of the Parkinson's Connect service [E1, E2a]. This aims to provide support to PwP-carer partnerships. The service is the first in the UK to offer educational, emotional, physical, and psychological support to carers – as well as family and friends of PwP – from the outset of the carer journey, independently from the PwP. This is the first formal recognition of the role of the carer as a valued partner to the care system to keep PwP at home for as long as possible. Users of the services can self-refer [E2b] or be referred by professionals at any point and have access to support via various forms of communication, including website, text messages, phone calls, printed information, podcasts, and face-to-face conversations.

Parkinson's Connect is now an integral part of the NHS care pathway advocated by Parkinson's UK. Implementation is currently underway in Northumbria, Cornwall, and North East London. This is part of a plan to extend it to 10 NHS services – reaching 15,000 PwP – by the end of August 2021 [E1, E2b], and to the whole of the UK from late 2021, although the expansion has been slower than anticipated because of the COVID-19 pandemic [E2; E1, p2]. 118 people (91 PwP and 27 carers) were referred at diagnosis between January 2020 and December 2020 and received additional individualised support [E1, p3]. Implementation barriers and facilitators are being systematically recorded and will inform the roll-out of the service nationally.

In addition, in 2019, Parkinson's UK's Underserved Group created a leaflet titled 'Caring for your resident with Parkinson's' [E3a] to give guidance to care homes on how to look after PwP in their care homes. The content featured contributions from Hand's research [R4], including information on the importance of residents getting their medication on time [E3a, p8] and looking out for their mental health [E3a, p7]. Almost 1,600 printed copies of this booklet have been distributed and it was viewed more than 500 times online between November 2019 and November 2020 [E3b].

4.2 Impact on national policies and guidelines

One of the key functions of Parkinson's UK is to campaign for better care for PwP and regularly respond to Government consultations. The Head of Policy and Campaigning explained that

'Results from Annette's research have been incorporated extensively into Parkinson's UK policy and campaigns work' [E1, p1]. This includes Parkinson's UK consultation responses to the National Institute for Clinical Excellence (NICE) guidelines for supporting adult carers (NG150, 2020 [E1, p1]) and for treating chronic sialorrhoea, a problematic secondary symptom of PD (2019, TA605, [E1, p1]).

Hand's research demonstrated that informal carer mental health worsened as a result of being a carer [R2]. Evidence from this research informed an All-Party Parliamentary Group (APPG) made up of professionals, PwP, and their advocates, demonstrating dissatisfaction with current mental health services. The final report, 'Mental Health Matters Too' (2018), referenced the research findings [E4, p39], highlighting the need for carers' mental health to be taken into consideration. As a direct result of the research, the report recommended that *'carers and family members should be supported in addressing their own mental health concerns by [healthcare] professionals and should be signposted to Parkinson's UK support services'* [E4, p30]. This now includes Parkinson's Connect (as above).

These research findings were then included in Parkinson's UK's co-development of the NHS RightCare Progressive Neurological Conditions Toolkit (2019) [E1, p1]. The toolkit was supported by NICE and created to support health systems understand the priorities in care for those people who are living with neurological conditions, including PD. Hand's research mainly fed into the Mental Health support content [E5, p8], which acknowledged the importance of meeting the mental health needs of carers.

4.3 Impact on PwP and their carers

The findings from Hand's research and the publication of the recommendations in the APPG 'Mental Health Matters Too' report led Northumbria Healthcare Trust's Parkinson's Specialist Service – which runs clinics in the region to support 1,600 PwP – to incorporate a new Parkinson's recording template on the nationwide primary care recording system SystmOne, used as part of a broader move away from paper-based systems in the NHS. Hand created the template based on her research, and it includes a systematic and proactive assessment of caring arrangements and carer strain under 'Social Changes'. There is now a clear identification of care needs, facilitating advanced care discussions and addressing carer issues such as strain and mental health, which were not previously considered. In order to ensure coordination, all General Practitioners (GPs) and other healthcare services can access the template, which is currently available to 96 GP practices in the North East. The new process prompts referrals for formal care and embeds carers' assessments, enabling PwP to remain at home for as long as possible, or ensuring a smooth transition into a care home. This benefits informal carers, ensuring their needs are being met by a more carer-friendly NHS. Between April 2017 and November 2020, a total of 1,315 people have been entered as carers in SystmOne [E6a, E6b]. Being identified as an informal carer then facilitates further interventions to help reduce strain both for the PwP and carer. Examples include referrals to the Parkinson's Connect service [E6b, p1], social services, talking therapies [E6b, p2], and befriending services that allow PwP and their carers to have some time apart [E6b, p3]. Following the success of this regional work, Parkinson's UK is currently developing a national template for primary care, although the roll-out has been delayed by the ongoing COVID-19 pandemic.

Offering consistent, responsive, and direct support to carers as a result of Hand's research has meant a great deal to carers under strain. Carers often struggle with the guilt of taking care of themselves, and as a result, are often tired, overwhelmed, and in need of respite. A [text removed for publication] is the carer for her husband [text removed for publication], who has complex PD, is now unable to walk and needs support with many medications and personal care. Since 2015, they have been part of the Northumbria Care Needs Project. Since the role of the carer has been formally recognised, she now feels:

'that when we come to clinic how I am doing is just as important as how [text removed for publication] is doing ... I am made to feel a very important part of the care team and I know I can talk to [Annette] about anything, and this support is my lifeline. We talk about

Impact case study (REF3)

how I am coping and managing and that makes such a difference to me ... Knowing that there is someone that takes my needs into consideration too and really does care about us both makes such a difference and has really helped me to continue in my caring role for [text removed for publication]' [E7].

M [text removed for publication] is the main support and carer for his wife, who was recently diagnosed with PD. They were referred to the PD Connect project and received trustworthy and up-to-date information and advice.

'We now understand that it is very important to support each other and for me to provide reassurance and positivity when required ... I am grateful that this support [from a partner or someone] is acknowledged by the project by taking the time to make sure that we are supported as well' [E8].

5. Sources to corroborate the impact (indicative maximum of 10 references)

Ref.	External Source of Corroboration	Link to Impact
E1	Testimonial - Laura Cockram, Head of Policy and Campaigning and Katie Goates, Professional Communications and Engagement Programme Manager, Parkinson's UK EMAIL: Katie Goates, Parkinson's UK	Confirms use of research for Parkinson's UK and consultation responses and development and impact of Parkinson's Connect project
E2	a) Parkinson's Connect project plan blueprint b) 'Parkinson's Connect: Our New Support Service' webpage, 25 February 2020 (accessed 21.01.21)	Provides details of Parkinson's Connect project and referral pathways
E3	a) 'Caring for your resident with Parkinson's' leaflet b) Email from Parkinson's UK	Confirms production and viewing statistics for leaflet
E4	All Party Parliamentary Group (APPG) Report: 'Mental Health Matters Too', May 2018	Hand's research cited p39
E5	RightCare Progressive Neurological Conditions Toolkit, NHS guidance, August 2019	Confirms Parkinson's UK input p82
E6	Patient Referral data from SystmOne a) Email: Andrew Fletcher, Parkinson's UK (8th December 2020) b) Data update and screenshots from SystmOne (20 December 2020)	Confirms number of people recorded due to SystmOne changes and interventions
E7	Testimonial – A [text removed for publication], Carer of PwP	Confirms value of support for carers of PwP of research
E8	Testimonial – M [text removed for publication], Carer of PwP	Confirms the value of support from Parkinson's Connect for PwP and informal carers