

UK PARKINSON'S

Excellence
Network



Providing better support to people with Parkinson's in the community and preventing unnecessary hospital admissions





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At times, people with Parkinson's may require a short stay in hospital. However, there are various reasons for trying to avoid hospital admissions where possible. For example, a recent survey of hospital admissions in England (2009–2013) suggested that people with Parkinson's had higher rates of emergency admissions, spent longer in hospital and were more likely to die while there than other patients.¹ These admissions also cost nearly £200million annually.¹

Going into hospital can be an anxious time for anyone, but there may be further concerns for people with Parkinson's. This may include being cared for by people who may not know a lot about the condition or making sure that they can continue to take their Parkinson's medication on time.

Between 2009 and 2013, there were 324,055 admissions of Parkinson's patients, of which 72% were non-elective.¹

As part of the UK Parkinson's Excellence Network, professionals came together and discussed what can be done to better support people with Parkinson's in the community and prevent unnecessary hospital admissions. We used this feedback as a springboard to create this information sheet.

The ideas in this document have been collected from around the UK. There is great variation in access to finances and resources across regions, so not all will be applicable locally. However, these ideas are potential ways you could help prevent hospital admissions through community services for the people you work with.



“We carry out domiciliary visits to those patients who are housebound. We make sure we see all individuals at home annually to assess their condition and medication, but also to see if they are able to manage at home independently.”

Accessing community crisis support

Managing Parkinson’s in the community, particularly at times of increased need that might lead to an unplanned admission, could be improved by ensuring rapid access to appropriate support. Knowing what support is available and identifying the signs of worsening symptoms early can help.

These are some ways in which you could improve access to community crisis support for people with Parkinson’s:

- Make sure patients are aware of available community services and how to access them. Being clear about where to go for support before reaching crisis stage (and when emergency services are necessary) could prevent unnecessary emergency admissions. Provide patients with a list or flowchart of ‘SOS’ community teams to clearly show whom they can contact, and when.
- Provide rapid access for patients with urgent problems by allocating fast track or emergency clinic slots during regular clinic hours. These could facilitate early assessment and triage to **rapid response teams**, without unnecessary involvement of acute hospital-based services. These teams could provide a short burst of extra multidisciplinary support to deal with a crisis outside of hospital.
- Consider **alternative ways** in which people with Parkinson’s can **access your support** in the community. For example, telemedicine, such as using telephone advice services or consultations by skype and email, can provide rapid access for assessment, support and consultation, especially where patients live remotely or may find it difficult to reach a clinic. Technology can be used to monitor a patient’s condition, and use of video or skype can allow assessment of symptoms without the need for a face-to-face appointment.
- If patients are able to contact the specialist Parkinson’s team in an **emergency**, ensure they have a **single point of contact** so that they can be promptly managed, reducing the need for secondary care.²

Planning ahead and anticipatory care

Planning ahead for times when a person with Parkinson's may need extra support can avoid unnecessary hospital admissions. A recent cross-sectional analysis of English hospital admissions data found that the most common reasons for hospital admission were pneumonia (13.5%),

motor decline (9.4%), urinary tract infection (9.2%), and hip fractures (4.3%).¹

Being aware of common reasons for hospital admission means you can set up anticipatory support and care to reduce the risk of them occurring. This allows problems to be dealt with promptly in the community before they reach a crisis point that requires emergency admission.

These are some ways in which you can **plan ahead and provide anticipatory care** for people with Parkinson's:

- Within your service, promote **anticipatory care planning** for people with Parkinson's. Anticipatory care is about planning for changes in a person's condition that might reasonably be expected. Plans should be specific, tailored to each person and include strategies for self-management. (See Appendices A and B for resources to help with anticipatory care planning).
- Ask patients, and their family or carer, what is important to them, **what support they need on a regular basis** and **what would help if their condition worsens**. The needs of carers should also be considered to make sure they can support the person with Parkinson's at home. Certain symptoms, including depression, anxiety and hallucinations, are related to carer stress, which may make an admission more likely.³ Patients and their carers will know what has or has not been helpful in the past. Ensure plans are reviewed regularly to incorporate any relevant changes in a person's condition.
- **Identify patients who are more at risk**, particularly those who have previously been admitted to hospital. Assess the reasons for their admissions and develop plans to address

the causes, reducing the risk of further admissions.

- **Advise patients on healthy living**, including eating a balanced diet, staying hydrated and keeping active. If people need support to manage their general health, refer them early to the appropriate professional or service.

For example, people with Parkinson's may experience falls and may be at greater risk of fractures due to decreased bone density. Anticipatory care to reduce falls and fractures may include regular medication reviews, encouraging exercise and ensuring they consume enough calcium and Vitamin D.

They may also benefit from a referral to a physiotherapist who can help improve posture and general muscle weakness or an occupational therapist who can help with adaptations to make their environment safer.

- Where admission is unavoidable, **agreed discharge plans** should already be in place where possible. These can improve the transition of patients back into the community, and reduce the chance of readmission.⁴



“This coming Monday sees the last day of my four-week self-management course. We have covered everything from medication to physiotherapy to occupational therapy to speech to exercise to you-name-it! It has certainly made me aware of how much I can manage my own life while being aware of what help is available to me – and making full use of that help!”



“Do things differently, embrace technology... there should be a ‘gold standard’ of support and care across the country.”

Empowerment and self-management

Self-management has been shown to increase quality of life and self-efficacy in individuals with chronic conditions, as well as benefiting the healthcare system by decreasing hospital readmission, service demand and costs.⁵

You can support and facilitate people with Parkinson’s to self-manage their symptoms and stay as well as they can. Self-management can be achieved when professionals work with patients, their family and carers, to develop knowledge and skills that support self-reliance.⁶ This may prevent symptoms deteriorating to the point where an admission is needed.

People with Parkinson’s are most likely to be admitted to hospital due to pneumonia, Parkinson’s-related symptoms, urinary tract infection, and hip fractures.¹

These are some ways in which you can help people with Parkinson’s to develop the skills and confidence to manage their condition, maintain independence and stay as well as they can:

- Ask the people with Parkinson’s you work with for their views. Find out what support they find useful to help them manage their condition day to day and if their condition worsens.
- Being informed is key to self-management. Refer people with Parkinson’s to resources, such as those produced by [Parkinson’s UK](#), which can help them to learn more about living with Parkinson’s and some of the ways other people have found to manage their condition. They might also find it helpful to talk to their Parkinson’s local adviser or attend a group where they can share self-management techniques with others living with Parkinson’s.
- People with Parkinson’s might find it helpful to be copied into correspondence about their care. This means they are fully informed, and they have a record of their symptoms and treatments.
- Make sure that patients are aware of and make use of community supports available to them. These may be local volunteer-led services or charities, such as [Age UK](#), [Age NI](#) or a Parkinson’s UK local group. Parkinson’s UK also run a free self-management programme for people with Parkinson’s, partners and carers to learn more about self-management and planning for the future. For more information please visit parkinsons.org.uk/selfmanagement

Working together

People with Parkinson's need to be supported by a range of health and social care professionals working together to provide high quality, consistent care. Fostering strong links between different care providers within the multidisciplinary team could improve the support for people with Parkinson's in the community.

Coordinating the care received from different agencies will ensure patients receive the right

interventions, treatment or support at the right time, reducing the need for crisis care or a hospital admission.



“I think palliative care needs, and particularly issues like advance care planning, are becoming increasingly recognised as important areas to address in Parkinson’s.”

Here are some ways you can make sure professionals work together to better support people with Parkinson's in the community and prevent unnecessary hospital admissions:

- To coordinate care being delivered by a number of different professionals and agencies, an identified key worker or case manager could be appointed. They can form a link between all the involved professionals, and keep an overview of the patient's support needs.
- Parkinson's nurses offer care at home or close to home in nurse-led clinics, and evidence shows high patient satisfaction among those with access to specialist nurses.⁷ You can build a business case for including a Parkinson's nurse in your team. Such nurses can deliver expert, accessible care at all stages of Parkinson's and on average save £80,000 in unplanned admissions a year.⁷ They are therefore an excellent resource to support people with Parkinson's in the community and avoid unnecessary and costly hospital admissions.
- Some professionals, such as GPs, may work with people with Parkinson's on an irregular

basis. However, while they may have few patients with Parkinson's to care for in their surgery, they can play a major role in supporting a person with Parkinson's to manage their condition in the community.

Local specialist Parkinson's services may be able to provide expertise and training to improve the knowledge of those who have less experience of working with Parkinson's. GPs and community services, including care homes and domiciliary services, need to have good relationships with specialist services, and could be involved in local Parkinson's networks.

- Where local health and social care services are not integrated, you could nominate a Parkinson's champion to act as a link. This could be a Parkinson's nurse or other professional with experience and knowledge of the condition. They could engage in training and education, as well as outreach and networking.



On average it costs £1,417 for a planned and £3,338 for an emergency admission.¹



“Clear channels of communication have been set up, with the nurse providing the first contact for the GP and patients, and then the more serious issues being escalated to me (the consultant). Additionally, there is a palpable increase in the understanding of neurology in the community. Overall, it has been a great advance in the community, in a relatively short time.”

Resources

The following resources were developed by Peter Smith (Parkinson’s nurse, Milton Keynes Primary Care Trust) and Jodie Cooke (Parkinson’s nurse, Coventry and Warwickshire Partnership NHS Trust). They list various complications experienced by people with Parkinson’s and what to do about them.

[Appendix A Anticipatory Care Plan: For patients with Parkinson’s at home with a care package or in a residential/nursing home setting.](#)

[Appendix B Anticipatory Care at Home](#)



The total cost of Parkinson’s admissions over 4 years was £906,617,908.¹



References (click to follow the link)

¹Low V, Ben-Schlomo Y, Coward E, Fletcher S, Walker R, Clarke C (2015) [Measuring the burden and mortality of hospitalisation in Parkinson’s disease: A cross-sectional analysis of the English Hospital Episodes Statistics database 2009–2013.](#) Parkinsonism and Related Disorders, 21: 449–454.

²Huntley A, Lasserson D, Wye L et al., (2014) [Which features of primary care affect unscheduled secondary care use? A systematic review.](#) BMJ Open, 4: e004746.

³Oh JS, Lee JE, Lee PH, Kim JS (2015) [Neuropsychiatric Symptoms in Parkinson’s Disease Dementia Are Associated with Increased Caregiver Burden.](#) J Mov Disord, 8(1): 26–32.

⁴McMartin K. (2013) [Discharge planning in chronic conditions: an evidence-based analysis.](#) Ont Health Technol Asses Ser, 13(4): 1–72.

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⁶Holman H and Lorig K (2004) [Patient Self-Management: A Key to Effectiveness and Efficiency in Care of Chronic Disease.](#) Public Health Reports, 119: 239–243.

⁷Parkinson’s UK (2011) [Parkinson’s nurses – affordable, local, accessible and expert care: A guide for commissioners in England/Northern Ireland/Scotland/Wales.](#)