

# Influencing planning to improve the quality of Parkinson's care in England

**This short guide enables you to influence commissioning, by making the case for high quality, cost-effective care for people affected by Parkinson's.**

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## **Know your population**

### **What you should do**

Identify your Parkinson's population. Look at the most recent census data (2011). Around one in every 500 people has the condition. Dividing the total number of people in your area by 500 should give you a good estimate of your population. For more detailed information, you could look at GP registers in the area.

Segment your population into the four stages of the condition by the percentage affected: diagnosis (11%), maintenance (40.4%), complex (33.6%) and palliative (15%). Think about what care each group is likely to need.

Don't forget to include people with other forms of parkinsonism, including dementia with Lewy bodies, progressive supranuclear palsy (PSP) and multiple system atrophy (MSA).

### **Why you should do it**

Profiling your population is the first step to understanding the needs of people with Parkinson's in your area. Once you know how many people are living with Parkinson's and what demand exists in different stages, you can plan services accordingly.

## **Get smart with data**

### **What you should do**

Check out the current Parkinson's data. Start with the [neurological data set](#). What are your admission rates, length of stay and readmission rates? How do your figures compare to national averages?

### **Why you should do it**

Analysing your performance is an important step. It equips you with the knowledge you need to improve quality and make services more efficient.

Unplanned admissions are expensive and often result from an avoidable crisis, so explore why people with Parkinson's are being admitted. For example, are your admissions higher among people with Parkinson's compared to the general population? How do they compare with unplanned admissions in other areas?

## **Promote the self-care agenda**

### **What you should do**

Check people with Parkinson's and their carers can access information about the condition and about the support and services available to help them manage it.

Parkinson's UK provides evidence-based, accredited information on all aspects of the condition and can signpost people with Parkinson's and their carers to local information and support services. Material is available on our website and through our publications and other resources. Visit [parkinsons.org.uk](https://parkinsons.org.uk) to find out more.

The charity also runs self-management programmes for people with Parkinson's, their partners and carers. For more information, visit [parkinsons.org.uk/selfmanagement](https://parkinsons.org.uk/selfmanagement)

### **Why you should do it**

Self-management has the potential to improve health outcomes, reduce unplanned hospital admissions and improve the patient experience for people with Parkinson's – but people need appropriate information and support to do this. The information, services and support that Parkinson's UK provides are available for free to people with Parkinson's, their family, carers and health and social care professionals.

## **Ensure neurology is in your local joint strategic needs assessment**

### **What you should do**

Make sure there is a joint strategic needs assessment for neurology across both health and social care.

### **Why you should do it**

A joint strategic needs assessment will help you understand the level of neurological health and social care demand amongst your population, including unmet needs and service gaps. It pulls together all the information available about what local people need and major issues that have to be addressed.

## **Promote better medicines management**

### **What you should do**

Check that there is a policy in place to make sure that people with Parkinson's receive their Parkinson's medication on time, every time, across all care settings, including in hospital, in care homes or in a person's own home. This will mean working with a wide range of professionals, including doctors, nurses and care workers.

Support should be available to enable people with Parkinson's to manage their own Parkinson's medication if they are able to do so.

Many community pharmacies offer a Medicines Use Review service, which gives people with Parkinson's the opportunity to discuss their medications with a pharmacist, and raise any

concerns or queries. Community pharmacists can also offer support about taking medication, and advise on over-the-counter medicines, which may interact with prescribed medicines.

Parkinson's UK runs a campaign called Get It On Time to highlight the importance of people with Parkinson's getting their medication on time, every time. For more information, visit [parkinsons.org.uk/getitontime](https://parkinsons.org.uk/getitontime)

### Why you should do it

If people with Parkinson's are unable to take their medication on time, it leads to symptoms becoming uncontrolled and can increase their care needs considerably. It can increase the length of a hospital stay and the risk of complications. Effective medicines management is therefore, a key part of avoiding preventable harm and should be seen as an important aspect of promoting patient safety.

A good medicines' management programme supports staff education and knowledge about Parkinson's, and leads to better management of the person with Parkinson's in the longer term.

Community pharmacy Medicine Use Reviews can ensure medication regimens continue to be safe by improving a person's understanding about the medications they take and by emphasising the importance of taking drugs on time.

## Introduce integrated, multidisciplinary teams

### What you should do

Ensure integrated, multidisciplinary teams are in place and that wherever possible, seamless, cost-effective services are provided across social, primary, secondary and tertiary care. Consider whether a greater skill mix will support this.

### Why you should do it

If you co-ordinate services and practice anticipatory care, problems can be identified early and interventions put in place quickly. This maintains people with Parkinson's quality of life and independence – while ensuring costly emergency hospital admissions, transfers to care homes and crises are kept to a minimum.

## Focus on end of life care for Parkinson's

### What you should do

Ensure people with Parkinson's are specifically mentioned in your long-term condition plans, to actively improve the health outcomes and experiences of those in this group who are approaching end of life.

### Why you should do it

As well as improving peoples' experiences and wellbeing, well-commissioned and organised end of life care brings efficiency savings and reduces avoidable admissions. This is why end of life care has a dedicated quality, innovation, productivity and prevention (QIPP) work stream.

## **Link into strategic clinical networks**

### **What you should do**

Look at ways to strengthen relationships between health and social care professionals, commissioners and voluntary sector groups who support people with Parkinson's.

### **Why you should do it**

Strategic clinical networks focus on priority service areas to bring about improvement in the quality and equity of care and outcomes of their population using an integrated, whole system approach. Networks bring together those who use, provide and commission the service to improve outcomes for complex patient pathways.

Networks operate in partnership with commissioners (including local government), supporting their decision making and strategic planning. They work across the boundaries of commissioner, provider and voluntary organisations.

## **Work with Parkinson's UK and the voluntary sector to improve patient outcomes**

### **What you should do**

Be aware of the outcomes that people living with Parkinson's want to achieve. Work with the voluntary sector to help you to support people with the condition to achieve their goals.

### **Why you should do it**

Parkinson's UK and other voluntary sector organisations support people living with Parkinson's to get their voice heard. They can work with you to use people's experiences of care to shape more effective services.

Parkinson's UK provides a wide range of support for statutory organisations and health and care professionals. Through the UK Parkinson's Excellence Network it offers support with commissioning and service improvement, professional networks, education and workforce development.

The charity also provides support directly to people living with Parkinson's and their families through its information resources, support services, helpline, self-management programmes and local groups.

## **Educate your workforce about Parkinson's**

### **What you should do**

Make sure Parkinson's education courses and events are provided and promoted locally for all professionals who work with people with Parkinson's.

The UK Parkinson's Excellence Network can help you find the right Parkinson's courses and training. To find out more, visit [parkinsons.org.uk/education](https://parkinsons.org.uk/education)

### **Why you should do it**

It's important to provide education for everyone involved in the care of people with Parkinson's. That includes general practitioners and hospital teams, as well as care home and social services staff. Give people regular opportunities to brush up in this complex area, to make sure patients are getting the best, most up-to-date care possible.

## More information

Please contact [serviceimprovement@parkinsons.org.uk](mailto:serviceimprovement@parkinsons.org.uk) if you want to discuss any of the issues raised in this resource.

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**The UK Parkinson's Excellence Network is the driving force for improving Parkinson's care, connecting and equipping professionals to provide the services people affected by the condition want to see.**

The tools, education and data it provides are crucial for better services and professional development.

The network links key professionals and people affected by Parkinson's, bringing new opportunities to learn from each other and work together for change.

Visit [parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)