

Influencing planning to improve the quality of Parkinson's care in Northern Ireland

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

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. What are your admission rates, length of stay and readmission rates? How do your figures compare to UK 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 self-management

What you should do

Check people with Parkinson's can access information about their 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 to local information and support services. Material is available on our website and through our publications and other resources. Visit 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

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.

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

The Parkinson's UK Expert Reference Group also shares good practice and how this can be implemented in hospitals. They have produced updated 'nil by mouth' and availability of medication guidelines. The group also offers education for healthcare professionals on the importance of timings of Parkinson's medication. For more information about the group, contact Esther McQuillan on **0344 225 3683** or emcquillan@parkinsons.org.uk

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.

Highlight Parkinson's with local commissioning groups and integrated care partnerships

What you should do

Look at ways to ensure that the needs of people with Parkinson's are considered by local commissioning groups and integrated care partnerships.

Why you should do it

Local commissioning groups are responsible for the commissioning of health and social care by addressing the care needs of their local population. Integrated care partnerships play a critical role in improving the management of long-term conditions through greater integration across primary, secondary and community care. Raising awareness with commissioners of the needs of people with Parkinson's is crucial to making improvements in complex patient pathways.

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 to find the right Parkinson's courses and training. To find out more, visit 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 if you want to discuss any of the issues raised in this resource.

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