

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

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 living 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 your current Parkinson's data. What are your hospital admission rates, length of stay and readmission rates? How do your figures compare to Wales and UK averages?

You should also gain an understanding of the specific pressures on local services, such as Parkinson's nurse caseloads, succession planning issues for clinicians, unfilled posts, waiting times for reviews and access to other services like therapies provision.

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-management agenda

What you should do

Check people with Parkinson's 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 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 the 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 healthcare professionals.

Ensure that your Local Health Board has a current Neurological Conditions Delivery Plan which addresses services for people Parkinson's

What you should do

Ensure that your Local Health Board's Neurological Conditions Delivery Plan is in place and that the needs of people with Parkinson's are incorporated into the current priorities and outcomes.

Why you should do it

Every Local Health Board is required to produce a Neurological Conditions Delivery Plan that takes account of local needs and reflects the priorities set by the Wales Neurological Conditions Delivery Plan. The local plan should highlight areas where improvements are needed and should give you a clear description of how the Local Health Board is working to achieve them.

It is particularly important to make sure that plans for supporting people with Parkinson's take account of the fact that care is provided in both neurology and care of the elderly services.

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

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 systems are in place to identify people with Parkinson's who are nearing the end of life, and offer individuals and families the opportunity for advance care planning.

Ensure that the local Neurological Conditions Delivery Plan and/or the Delivering End of Life Care Plan specifically addresses the palliative and end of life care needs of people with advanced Parkinson's across all care settings.

Why you should do it

Planning to provide end of life care and enabling people to participate in advance care planning improves the experiences of people with Parkinson's and their families. It also leads to efficiency savings and a reduction in avoidable emergency hospital admissions, and delayed discharge.

Link with local and national networks

What you should do

Identify and link with local and national networks or partnership groups to strengthen relationships between health and social care professionals, service planners and voluntary sector groups who support people with Parkinson's and their carers.

Why you should do it

Local and national networks should focus on priority service areas to increase the quality and equity of care and outcomes. By using an integrated, whole system approach, these networks can bring together those who plan for, use and provide services and improve outcomes for 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 have 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

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. Providing opportunities for all to refresh their knowledge of this complex condition will ensure patients get 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