Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 64
Ymateb gan: | Response from: Parkinsons UK Cymru

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor
Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?
Q1. Which of the issues listed above do you think should be a priority, and why?

Health and Social Care Workforce

Recommendation 3 of the Cross Party Group on Neurological Conditions report on the Inquiry into the implementation of the Neurological Conditions Delivery Plan states that Welsh Government must: *"Commit to workforce development and commission a strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with a neurological condition in a timely manner in a timely place."* This recommendation was partly accepted and is particularly pertinent to Parkinson's.

Parkinson's is the fastest growing neurological condition in the world[1] and the Parkinson's population in Wales is set to increase by around one fifth to approximately 9,100 by 2030. Given this stark reality, an NHS workforce that is fit for a future where an increasing number of people will be living with Parkinson's (in addition to other comorbidities) is an immediate priority to ensure we can meet the needs of this population.

The NICE Guidance on Parkinson's references people suspected of having, or diagnosed with, Parkinson's should be diagnosed, regularly reviewed and readily able to access specialist Parkinson's expertise. At present there is an inequity of access to Parkinson's specialists (both at consultant level and Parkinson's Nurse Specialists) across Wales effectively creating a postcode lottery.

Succession planning is not always sufficiently robust in health boards to ensure continuity of access for people and there continue to be examples, across different parts of Wales, where insufficient succession planning and recruitment challenges have left people without any access to a specialist for long periods of time (something which is unacceptable when living with a degenerative neurological condition) or created unsustainable pressures for staff trying to provide cover for patients.

Education in Parkinson's for the health and social care workforce must be developed as a matter of urgency in order for the workforce of the future to fully understand the complexities of living with Parkison's, a condition which has more than 40 motor and non motor symptoms, many of which are poorly understood, not only by the general population but by staff across our health and social care workforce who do not specialise or work directly with people who have the condition.

A Healthier Wales refers consistently to a workforce that is skilled, motivated, sustainable and has capacity. With the Parkinson's population set to increase by 2030, we must take action on population needs based workforce planning now to ensure that we do not leave people without access to an expert Parkinson's workforce.

The Health and Social Care Committee should play a key role in holding the Welsh Government to account on its plans and progress to develop a workforce fit for our future that is rooted in population needs.

Support and services for unpaid carers

In summer 2021 Parkinson's UK conducted a survey of people affected by Parkinson's in conjunction with Lancaster University to explore the impact of lockdown restrictions.
Responses to the survey demonstrated that the impact of the pandemic on family members, friends and carers, particularly spouses or partners, has been considerable. 68% had taken on more caring responsibilities since the coronavirus restrictions started. 42% said the restrictions

were negatively affecting their mental health and 34% their physical health. Stress, boredom and loneliness were often reported, with some saying the situation had caused massive family strain.

The overwhelming majority of people with Parkinson's in Wales (87%) are aged over 65, and around 1 in 3 are aged over 80. It is therefore the case that those husbands and wives who are caring for their loved one with Parkinson's are likely already living with health challenges and comorbidities of their own.

We would welcome an inquiry into support for unpaid carers and would strongly recommend that the scope of any inquiry considers the impact that caring has on unpaid carers own health and wellbeing.

Access to COVID and non-COVID rehabilitation services

Access to speech and language therapy, occupational therapy and physiotherapy is an essential component of managing Parkinson's from diagnosis onwards. Access is patchy and inconsistent across Wales and within individual health boards. Experts, such as Parkinson's or neuro physiotherapists are few and far between. Once again, NICE recommendations regarding early and Parkinson's specific interventions (appropriate to stage of condition) are not being met.

During summer 2021 Parkinson's UK conducted a survey of people affected by Parkinson's in conjunction with Lancaster University to explore the impact of lockdown restrictions.
Many people told us that their Parkinson's symptoms had become worse since the restrictions began. Over a third experienced increased slowness of movement, stiffness and fatigue and over a quarter increased tremor, anxiety and sleep problems. Stress and isolation and reduced access to health care and exercise were seen as causes of deterioration.

Wales had the lowest number of respondents who decided to cancel appointments because they were worried about the coronavirus (8% for Wales, 15% for the UK.)

Cancelled appointments were seen by many as a contributor to deterioration of the condition and some were worried they were storing up future difficulties.

However, in respect of rehabilitation services essential for managing Parkinson's, Wales fared worse than the other UK nations in terms of appointments for rehabilitation services that were cancelled by the NHS during the pandemic.

Cancellation rates were as follows:

- 78% of physiotherapy appointments were cancelled across Wales (70% across UK);

- 76% of speech and language therapy appointments were cancelled in Wales, 57% across UK);
- 78% of occupational therapy appointments in Wales were cancelled, 55% across the UK).

It is welcomed that the Committee is already considering access to Covid and non-Covid rehabilitation services as a potential priority for the Sixth Senedd and we would support an inquiry into access to COVID and non-COVID rehabilitation services.

On occasion the collective term 'rehabilitation services' can mislead a little. People living with Parkinson's require access to these services from the onset of their condition and as it progresses in order to learn how to adapt to living with the changes that come with a degenerative neurological condition, including day to day self management techniques that can support quality of life at different stages of Parkinson's.

We would urge that groups, such as those with Parkinson's, that were already experiencing unequal access to rehabilitation services prior to the pandemic are front and centre when considering this issue. People with both positive and negative experiences of being able to readily access rehabilitation services can offer real insight into how it impacts on the day to day management of living with a long term condition such as Parkinson's.

Access to services for long-term chronic conditions

Services for people with Parkinson's were disconnected before the pandemic. People with Parkinson's in Wales may follow a care pathway via Neurology or via another speciality, eg, Care of Older People (age may not necessarily be the part of the criteria for this decision and this in itself is an issue impacting access for some groups of people living with Parkinson's).

People may be seen by a general neurologist or a specialist in Parkinson's, they may or may not have access to a Parkinson's Nurse Specialist, and the access they have to other multi-disciplinary services appropriate to the management of Parkinson's may depend on where the specialism for Parkinson's is sited within a particular health board structure.

Importantly, it's not clear if/ how the forthcoming Welsh Government Quality Statement for Neurological Conditions will apply to Care of Older people. Yet, for Parkinson's, Care of Older People services is where a substantial number of patients access their NHS care and where Parkinson's expertise lies.

As mentioned in the Cross Party Group on Neurological Conditions report on the Inquiry into the implementation of the Neurological Conditions Delivery Plan, while the Neurological Conditions

Delivery Plan served as a useful catalyst to progress and the development it has not yet resulted in the degree of change which should be expected, despite being in place since 2014.

Clear and equitable pathways of care for people with Parkinson's are essential as the Parkinson's population of Wales grows. The forthcoming Quality Statement for Neurological Conditions refers to how "the NHS Executive will support the local implementation of nationally agreed, optimised clinical pathways."

The Health and Social Care Committee will have a critical role to play in holding the Welsh Government to account on all aspects of the Quality Statement to ensure that tangible progress is evident to those people living with neurological conditions in accessing their day to day care.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd

Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

a) gwasanaethau iechyd;
b) gofal cymdeithasol a gofalwyr;
c) adfer yn dilyn COVID?

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

a) health services;
b) social care and carers;
c) COVID recovery?

Gwasanaethau iechyd

Health services

In our pre Senedd election briefing to all candidates, we flagged the imperative for mechanisms to be put in place at a Wales wide level to ensure that people with Parkinson's get their Parkinson's medication on time in hospital or a care home, every time, in line with our ongoing UK wide 'Get It On Time' campaign.

NICE Quality Statement 4 says that people who are in hospital or a care home take levodopa within 30 minutes of their individually prescribed administration time. Serious complications can develop if Parkinson's levodopa medication is not taken on time.

Of those in Wales going into hospital with Parkinson's 73% told us they didn't get their medication on time.(source Parkinson's UK Your Life, Your Services survey of people affected by Parkinson's 2018.)

In our briefing we called on the next Welsh Government to:

- Direct all health boards to implement specific procedures relating to the prescribing, supply and administration of Parkinson's medications in the hospital setting which mean that Parkinson's medication can always be administered on time.
- Direct all care homes to implement specific procedures relating to the prescribing, supply and administration of Parkinson's medications in the care home setting which mean that Parkinson's medication can always be administered on time.

While we acknowledge that this is an issue largely unique to Parkinson's, the consequences of people not getting their medication on time can be far reaching for both the individual and the health and social care system.

For example, if someone with Parkinson's has not received their medication on time or has missed a dose and symptom management declines, they may not be able to undertake a physiotherapy assessment that would otherwise, when medicated, have seen them fit to be discharged from hospital if their medication was controlling their symptoms.

People who repeatedly did not receive their medication on time while in hospital tell us that this has resulted in longer hospital stays as they struggle to get on top of symptom management and regain control of their Parkinson’s symptoms that were, often, well managed before admission. Sometimes, if repeated doses of medication are delayed or missed, people do not regain the level of control of symptoms that they previously had and, in turn, may require additional ongoing health and social care support.

We would wholeheartedly welcome the Health and Social Care Committee’s detailed consideration of this issue by way of an inquiry. We believe that there is much to do to ensure the basic right to receive your medication on time in order to effectively manage your condition when in hospital and negate the negative impact upon individuals and additional system pressures.

Positively, there are examples of where Parkinson’s medication management in hospital works well, demonstrating that there is scope for improvement with good practice and learning shared. However, to effect real change this will need a national steer.

Adfer yn dilyn COVID
COVID recovery

Use of digital technology - Whilst many people have been content to accept telephone/ video appointments during the height of the pandemic due to the exceptional circumstances, this does not necessarily mean that this method of engaging with the health service is the best for them or that they are wholly comfortable with this form of consultation.

Telephone/ video appointments may be challenging for people with more advanced Parkinson’s - for those with cognitive difficulties, speech and voice problems for example - and clinicians can’t so readily identify changes in motor symptoms without seeing an individual face to face

In conjunction with the points already highlighted under ‘health and social care workforce’, and taking into consideration everything that has been learned about service provision during the pandemic, it’s imperative that access to services for those with long term conditions such as Parkinson’s is developed in a person centred way.

Unrhyw faterion eraill

Any other issues

C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?

Q3. Are there any other issues you wish to draw to the Committee's attention?

Overarching re. Neurological Conditions:

The Cross Party Group on Neurological Conditions report on the implementation of the Neurological Condition Delivery Plan published in summer 2020 (based on the Group's inquiry prior to the start of the pandemic) made a series of recommendations to both address specific issues relating to the outcome indicators of the existing plan and for the future of improvements to neurological services in Wales for people living with neurological conditions.

The Welsh Government and the National Clinical Lead for Neurological Conditions accepted 8 of the 10 recommendations in full and 2 were accepted in part.

The Health and Social Care Committee should be instrumental in holding the Welsh Government to account on how it progresses in delivering against these recommendations. As a part of this, and at the appropriate point in time, the Committee could/ should seek, to engage with those groups that contributed to the CPG inquiry (as follows) to gather evidence on the progress being made against the recommendations:

- Individuals living with neurological conditions and carers
- Charities representing people affected by neurological conditions;
- Specialist clinicians;
- Royal Colleges;
- The Wales Neurological Alliance.

Health inequalities:

We, along with other health and social care charities in Wales, are calling for an inquiry across all Senedd Committees on tackling health inequalities in Wales. Meaningful progress will require coherent efforts across all sectors to close the gap and an inquiry undertaken by all Senedd Committees will enable Committees to consider what action each Welsh Government department is doing to tackle the root cause of health inequalities and put forward recommendations around where improvements are needed.

Inequalities specifically relating to Parkinson's - while Parkinson's does not discriminate, we know that, compounding the recognised health inequalities impacting the population at large across Wales, there are inequalities for people living with Parkinson's in terms of access to services and associated support across Wales including the following:

- access to services in rural and urban areas differ widely.
- services within healthboards do not have a consistent pathway of care for people with Parkinson's, experience of care will be determined by whether someone is a patient within neurology or Care of Older People services and what services can be

accessed therein.

- access to different Parkinson’s treatments - in particular, treatments for advanced Parkinson’s such as Deep Brain Stimulation and Apomorphine or Duodopa- varies across Wales with some health boards referring to/ prescribing such treatments in anticipated numbers while in other areas numbers remain negligable.
- signposting to third sector support from the NHS so that important support mechanisms such as benefits entitlement can be explored is inconsistent.
- physical (e.g. accessible transport) or digital access to peer support e.g. local Parkinson’s cafes/ online exercise classes varies enormously leading to exclusion from support services that can significantly improve self management and quality of life.
- access to specialist Parkinson’s care for people living in care homes is not consistent, adding to inequity for people living in residential care.

As part of an inquiry into health inequalities and how these may be addressed, the Committee should seek the input of those communities and groups of individuals living with conditions such as Parkinson’s, including those that are traditionally harder to hear from, to truly understand the specific needs of people living with all stages of the condition and the inequalities they experience as well as suggested solutions.