Parkinson’s UK in Scotland

Health and Sport Committee Inquiry into the Preventative Agenda
Response from

Which areas of preventative spending/ the preventative agenda would it be most useful for the Health and Sport Committee to investigate?

1. Access to exercise and other public health interventions, especially those delivered by the third sector

Improving population health and tackling health inequalities is essential, but it is important to recognise that it will not remove all the pressures on the NHS and social care.

Parkinson’s UK is acutely aware that Parkinson’s – in common with many other neurological conditions - cannot be prevented, and that prevalence is expected to rise as the population ages. The number of people living with Parkinson’s in the UK is expected to have increased by 28% in the decade to 2020.¹

Although medication and other interventions can help to manage some symptoms, there is currently no cure for Parkinson’s, and there are no treatments that can delay the progress of the condition. Medication becomes less effective and carries serious side effects, and people with Parkinson’s inevitably require increasing levels of care and support as their condition progresses.

Improvements in population health and wellbeing can help people to live better with Parkinson’s. People who are fitter, and with fewer preventable co-morbidities, will be better able to manage the impact of their Parkinson’s. There is also increasing evidence that physical exercise may prevent the development of Parkinson’s, and that it is particularly beneficial for people with Parkinson’s - and may even slow the progress of the condition, something no current medical or surgical treatment can offer.²

Parkinson’s UK in Scotland welcomes analysis of the impact of social prescribing and other schemes that enable people with long term conditions, disabled people and older people to access physical exercise. Has health and social care integration provided opportunities to expand the use of such programmes? And what is the role of the third sector in providing these?

2. The role of specialist multi-disciplinary care teams in supporting people with complex conditions

Many of the Scottish Government’s recent policy documents correctly emphasise the importance of multi-disciplinary working to enable the right intervention to be delivered at the right time. Parkinson’s UK in Scotland would welcome an inquiry into access to allied health professionals and specialist nurses, including via an integrated multi-disciplinary team for those with complex conditions such as Parkinson’s, where specific knowledge of a person’s condition is required.

¹ Parkinson’s UK, Parkinson’s in Scotland (2019)
² Parkinson’s UK, Physical Activity and Parkinson’s: A Literature Review (2016)
For people with Parkinson’s specialist multi-disciplinary support is a preventative measure, as people require tailored interventions to keep them as well as possible, and to anticipate and prevent crisis and acute deterioration. This approach is already embedded in Parkinson’s services across Scotland, and HIS Clinical Standards for Parkinson’s specify that a multi-disciplinary team approach to ongoing care is needed throughout the course of the condition. This care needs to be delivered by professionals with specialist knowledge of Parkinson’s, rather than a generalist team. Parkinson’s is a complex and very variable condition that affects every aspect of daily living. Treatment is highly individualised, and is characterised by bespoke medication regimes. A typical GP in Scotland will only see one new case of Parkinson’s every three years. SIGN Guidelines and HIS Clinical Standards make clear that people need to be diagnosed by a specialist, and that they need to be seen by specialist clinicians for ongoing review. Parkinson’s nurses have a key role in supporting individuals and carers with the immense impact of a person’s symptoms, recommending medication changes and supporting self-management.

People with Parkinson’s are at very high risk of emergency hospital admissions. Once admitted, they require longer hospital stays than people without the condition. Multi-disciplinary Parkinson’s care and support can anticipate and manage problems as or before they arise and prevent unnecessary hospital admissions. Early interventions from physiotherapists, speech therapists, occupational therapists and mental health professionals can help people with Parkinson’s to accommodate their symptoms and reduce risks arising from falls, choking or undertaking everyday tasks.

3. Improved access to social care
A major area of concern for people with Parkinson’s and families, as well as for other disabled people, is the lack of availability of social care services, including lower level interventions that can help people to stay well. Being properly supported at home, particularly with nutrition and adhering to prescribed medication can have a major impact on preventing sudden deterioration. Parkinson’s nurses tell us that some people are being admitted to care homes because there is insufficient access to support with Parkinson’s medication in the community.

We are aware of areas of Scotland where people have been told that no social care can be provided because of a lack of carers to provide the care that they need, and of many other cases where the care provided is insufficient to meet the needs of the person with Parkinson’s and / or their carer. Some people are forced into residential care - or to be admitted to or remain in hospital - because of the lack of home-based social care packages to support them.

4. Recognition and support for unpaid carers
Unpaid carers provide a huge amount of preventative care, which is largely unrecognised as such, and it would be worthwhile for the committee to investigate how greater carer support can enable more preventative care.

It is estimated that unpaid carers provide up to 80% of the costs of care provided to people living with Parkinson’s. In addition to practical support and ongoing
supervision of the person, unpaid carers usually know the person best, and have an unparalleled insight into the issues that the person with Parkinson’s is living with, which the person themselves may find difficult to identify or acknowledge. Health and social care teams need to recognise the importance of carers and involve them in shared decision making, where the person with Parkinson’s wants this.

Unpaid carers also need additional support to enable them to continue caring when they wish or are able to do so. This may include greater access to homecare services and suitable respite.

Those who care for people with more advanced Parkinson’s typically have extremely high needs for support because the person they care for has very significant care requirements. These can include complicated medication regimes, severe mobility problems, disturbed sleep, pain, communication difficulties, continence issues, mental health symptoms and dementia. People with Parkinson’s often live with advanced Parkinson’s for years, and the impact of caring for people with such high care needs over a long period takes its toll.

5. Frailty and death cannot be deferred indefinitely, but that anticipatory care planning can prevent unwanted and costly interventions

“Improving community care may postpone the need for hospital care, but it will make frail older people neither invincible nor immortal: mostly, they will simply need the care later.”

And the need for care is not just within the acute system. While the number of people who are living in care homes in Scotland has remained fairly consistent over the last few years, the proportion of residents with very high care needs have increased considerably. In 2016, both the number of people receiving care at home, and the number of home care hours received fell. Our experience of supporting people with Parkinson’s and those closest to them throughout Scotland supports the idea that these reductions in care may reflect budget and service pressures rather than reductions in need.

More than 800 people die each year with Parkinson’s mentioned on their death certificates in Scotland, and people with the most advanced Parkinson’s have quality of life as bad as – and in some cases worse than - those with terminal cancer and motor neurone disease (MND). However, we know that people with Parkinson’s are much less likely to have been involved in advance care planning, or to have received specialist palliative care input than those with other types of condition. The 2016 UK Parkinson’s Audit found that only 28% of people with markers of advanced Parkinson’s had any recorded discussion of end of life care issues. This places them at risk of receiving costly types of interventions that they don’t want, in places that they don’t want to be.

It is clear that services could do more to plan what will happen next when someone is admitted to hospital. Carers and families tell us that there is often little discussion about care options until professionals decide that the person should be discharged, and that this leaves people in a rush for decisions to be made. If a care home placement is recommended, or a homecare package is needed, there is often little time to consider critical decisions, and there is often a sense that people are being
asked to make a quick decision in a time of real crisis. This is echoed in relationships with social care services, with little time to ensure facilities are in place or to try and prepare a smooth transition for the person and those closest to them. Better planning and links between health and social care professionals should drive improvements in delayed discharge rates, as well as reducing the risk of revolving door admissions when someone is discharged from hospital too early and their condition deteriorates.

**How can health boards and integration authorities overcome the (financial and political) pressures that lead to reactive spending/ a focus on fulfilling only statutory duties and targets, to initiate and maintain preventative spend?**

Parkinson’s UK in Scotland believes that it is going to be very challenging to achieve these changes in a time of extreme budgetary pressure. It is inevitable that NHS boards and integration authorities will be driven to prioritise meeting their statutory duties and targets. There is a case for shifting the balance of targets to drive preventative spend.

We would emphasise the importance of statutory bodies and health professionals working with third sector organisations to provide access to community based health and lifestyle initiatives, including self-management courses, exercise initiatives and buddy schemes. However, we note that some of these services are folding or restricting access because of lack of funding from statutory bodies, so these funding lines must be protected.

**How could spend that is deemed to be preventative be identified and tracked more effectively? What is required in terms of data, evidence and evaluation to test interventions for producing ‘best value for money’?**

Parkinson’s UK in Scotland believes that there are opportunities to use service redesign projects to track preventative spend and its outcomes. This would enable value for money to be established, and reflects the evaluation work that we support NHS boards to undertake when a new Parkinson’s nurse is appointed.

**How can the shift of spending from reactive/acute services to primary/preventative services be speeded up and/or incentivised?**

It is important to recognise that not all spending in the acute sector is reactive spending. Specialist staff, who are often (though not always) based in acute services, have a key role to play in supporting people with complex conditions like Parkinson’s. However, there is more work to be done in terms of integrating allied health professional services so that they are able to work across traditional health and social care boundaries.

There may be a case for providing financial incentives for integration authorities who provide effective multi-disciplinary care to people with progressive conditions like Parkinson’s, where reductions in unplanned hospital admissions can be demonstrated.

**About Parkinson’s**

More than 11,000 people in Scotland people have Parkinson’s. About one in ten of these people are classified by ISD as at high risk of hospital admission in the next year.
Parkinson’s is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson’s often find it hard to move freely. Their muscles can become stiff and sometimes they freeze suddenly when moving. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact on peoples’ day-to-day lives. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden ‘freezing’.

About Parkinson’s UK
For more information, please contact our Parliamentary and Campaigns Officer, Tanith Muller, email: tmuller@parkinsons.org.uk, telephone 0344 225 3726.

We’re the Parkinson’s charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson's.

Find out more about us at www.parkinsons.org.uk

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15. Parkinson’s UK (2016) UK Parkinson’s Audit Reference Report