Carers (Scotland) Bill

Parkinson’s UK

Question 1: Do you support the Bill?

Parkinson’s UK strongly welcomes the Bill, which ought to improve support for those providing unpaid care to support people with Parkinson’s. As can be seen below, caring for someone with Parkinson’s can be extremely hard work, and the caring relationship typically lasts and intensifies over many years.

Parkinson’s UK would like to see some changes to strengthen the legislation and ensure that carers who need support are able to access it.

Our response is informed by our work with some of the 10,000 people in Scotland who have Parkinson’s and their unpaid carers, families and friends. Our team of Information and Support Workers covers the whole of Scotland, and provides free, confidential support and advice to anyone affected by Parkinson’s. A significant amount of their time is spent supporting carers of people with Parkinson’s.

It is estimated that informal carers provide up to 80% of the costs of care provided to people living with Parkinson’s. Carers can find that they have very high levels of involvement throughout the course of Parkinson’s.

Those who care for people with more advanced Parkinson’s typically have extremely high needs for support because the person can have 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.

In a recent survey, nearly two third of carers of people with Parkinson’s in Scotland were providing care for more than 50 hours a week, 79% of those caring for someone with Parkinson’s said that their caring role had had a negative effect on their own physical health and 85% reported a negative effect on their mental and emotional well-being. Yet three quarters of people caring for someone with Parkinson’s in Scotland had not had a carer’s assessment.

Question 2: What do you feel would be the benefits of the provisions set out in the Bill?

The main benefit of this bill is to give local authorities duties to identify and support unpaid carers. This considerably strengthens the current position which falls short of requiring local authorities to act. As noted above, the overwhelming majority of people who care for someone with Parkinson’s have no support from local authorities for their caring activities.

We particularly welcome the following provisions:
replacement of carers’ assessments with carers’ support plans. This terminology sounds less as though the person is being judged on their caring activities and more as though they are being supported to provide care.

removal of the requirement for the person receiving care to get this via local authorities in order that carers qualify for an assessment of their caring needs. This recognises the reality of providing unpaid care for people with complex health conditions like Parkinson’s. People with Parkinson’s often live with the condition for some time before they access local authority services because they receive their care and support through specialist multi-disciplinary teams (often based in NHS secondary care). Carers are typically closely involved throughout someone’s journey with Parkinson’s and can provide very high levels of unpaid care before local authority care is provided.

removal of the “substantial and regular” test. Some carers fail to meet this because Parkinson’s is a fluctuating condition, and the severity of people’s symptoms can vary from day to day – and even hour to hour. Some people with Parkinson’s have very intense support needs at certain times, but need less care the rest of the time.

introduction of the category of being able and willing to provide care. For us, the introduction of a measure of willingness to provide care is important, as nobody should be compelled to become an unpaid carer. However, we have some concerns that the retention of the requirement of a carer to be deemed “able” to provide care may have the effect of marginalising carers who provide care to someone else while having care needs of their own.

**Question 3: How do you feel the Bill could be amended or strengthened?**

In common with other voluntary sector organisations, Parkinson’s UK is concerned about the status of local and national eligibility criteria for accessing carers’ support. We would prefer to see national eligibility criteria, which would mean that everyone would be entitled to support on the basis of similar needs. Without this, we are very concerned that there will be considerable inequalities in services. We also believe that a minimum package of support for carers should be established in statute, to ensure that everyone can access basic services wherever they live.

Parkinson’s UK is also concerned that there is no requirement in the bill for carers’ support plans to include emergency and anticipatory care planning – though this is intended to be included in guidance. This is a major issue for carers who look after people with Parkinson’s, given that people with Parkinson’s are often at very high risk of unplanned hospital admission. We believe that carers’ support plans should be required to include emergency and anticipatory plans, and this should be on the face of the Bill.

On a related point, discharge from hospital can be a major challenge for carers of people with Parkinson’s, and in many cases, discharge marks an
increase the intensity of the caring role. We believe that the legislations should impose a duty on NHS Boards to include both inpatients and their carers in discharge planning from the point of admission onwards.

Overall, it is of concern that the NHS is mentioned so rarely in the draft bill, and that NHS Boards will no longer need to develop a carers’ information strategy. It is likely that this will have the consequence of reducing awareness of the essential role that unpaid carers have in supporting the people they care for. Parkinson’s UK would like to see additional duties on the NHS to recognise and support carers in their role, particularly in relation to identifying and signposting carers to support. This reflects the reality that many people with Parkinson’s and other long term conditions receive their care from NHS services, and may not be known to local authorities. We believe that this is likely to be a particular issue for people who receive their NHS support from services that are not subject to formal integration, such as those who receive their care via NHS neurology services, where links with the local HSCP may not be well developed.

Parkinson’s UK is disappointed that the Bill does not create a duty for local authorities to provide short breaks from caring for those who need it, and believes that this should be rectified. We believe that the duty should also specify that short breaks should be provided in accommodation appropriate to the person’s needs, reflecting the needs of people in the local area. Carers of people with Parkinson’s often report that it is challenging to get appropriate accommodation for short breaks, because of the complex care needs that people with Parkinson’s can have. Carers tell us that they refuse to take short when they don’t believe that the care provider have the facilities or trained staff to look after the person with Parkinson’s appropriately. People of working age with Parkinson’s often feel that it is inappropriate to take a break in a care home with residents who are very old and frail.

Many of those who care for people with Parkinson’s have long term conditions or are disabled themselves. As noted above, the requirement for carers to be deemed “able” to provide care may mean that these carers are not recognised. We would like to see an explicit acknowledgement that people with care needs can themselves be carers on the face of the bill.

We are concerned about the resource implications for local authorities, NHS, and voluntary sector services in the current climate. Delays in providing support, or responding to changing needs, can have a disastrous impact on carers, and there needs to be a system in place to make sure that those with the greatest need are able to access support as quickly as possible.

It is hard to see how the new system is going to work without local authorities, the NHS and voluntary sector having significant additional funding to provide support for carers. We are already hearing that the services needed to support carers simply are not there in many parts of Scotland and the Bill does not indicate that there are plans for additional resources to be provided to support this work.
Question 4: Is there anything that you would add to the Bill?

Please see above.

Question 5: Is there anything that you would remove from the Bill?

Please see above.

About Parkinson’s
About 10,000 people in Scotland people have Parkinson’s.

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. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact. 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’. There is no cure.

Parkinson’s UK