Introduction and context

Parkinson’s UK strongly welcomes the Committee’s Inquiry on age and social isolation, which is a major issue for people living with Parkinson’s in Scotland. We would like to emphasise that social isolation can be a problem for people of any age.

Most people living with Parkinson’s in Scotland are aged over 60. However, some people are diagnosed much younger. For younger people diagnosed with Parkinson’s, it can be doubly isolating to have a condition that is commonly associated with older people.

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. They report that many of their clients are very socially isolated, and that this can lead to significant problems.

This also reflects published research that shows that people with Parkinson’s typically report very sharp increases in social isolation as their condition progresses, with a very negative impact on quality of life.12

Social isolation can affect people in a range of situations, from people with Parkinson’s who live alone, to people who live in residential care or with partners or family members with whom they have minimal social interaction.

In addition to the factors that put anyone at risk of social isolation, people with Parkinson’s often have specific symptoms that can contribute to social isolation. As the condition progresses, these symptoms typically worsen. For example:

- Problems with mobility makes access to buildings and travelling difficult
- “Wearing off”, where medication stops working, and people have extremely limited mobility until the next dose takes effect, has a major impact on people’s ability to be away from their home or in social situations
- Mental health symptoms including apathy, depression and anxiety are very common and can prevent people from maintaining social networks
- Pain and fatigue have a significant impact on people’s ability to be social
- Cognitive impairment and dementia make it much more difficult for people to socialise
• Communication issues, including lack of clarity of speech, quietness, slowness of speech can make conversation difficult
• Many people find it embarrassing that they experience unpleasant and visible symptoms such as drooling, excess sweating, incontinence, tremor, swallowing issues, involuntary movements, changes in gait and facial masking. Some people with Parkinson’s have mistakenly been accused of being drunk in public. People with Parkinson’s report that other people’s attitudes and misunderstandings about their condition can have an enormous impact.

Unpaid carers of people with Parkinson’s are also at high risk of social isolation. People with more advanced Parkinson’s often require very significant levels of care and supervision, which severely limits opportunities for carers to maintain their social networks. People who provide unpaid care for people with complex neurological conditions like Parkinson’s experience very high levels of stress and other mental health issues which both contribute to - and can be exacerbated by - social isolation.

1. Prevalence of social isolation in urban and rural settings
Parkinson’s UK believes that social isolation can occur in all types of settings, from remote and rural settings to inner cities and all points in between. If someone cannot easily leave their house, they are at higher risk of being socially isolated whatever lies beyond their doors.

However, our experience is that lack of public transport can increase social isolation in rural areas. This is particularly the case where a person has had to give up their driving licence. Poor public transport can make it impossible to take up opportunities for social interaction.

Rural areas may also have fewer local opportunities for social interaction, and some voluntary sector initiatives find it prohibitively expensive to offer support to small numbers of people living in remote and rural settings, which can mean that people who live rurally are additionally disadvantaged.

2. Impacts of social isolation, for instance loneliness, ill-health
People with Parkinson’s who are also socially isolated report poorer Quality of Life. Parkinson’s is a very complex and difficult condition to live with. People whose Parkinson’s symptoms include depression, apathy and anxiety will often experience more severe symptoms if they are socially isolated.

People who are socially isolated may also miss out on the insights that other people can make about our health. Family, friends and acquaintances can have an important role in providing a perspective that the person may not have noticed themselves, which can prompt individuals to seek additional treatment or support to enable them to manage their lives better. This may range from seeking aids and adaptations, to addressing issues
around mental health and cognitive symptoms that are common in Parkinson’s, such as depression, anxiety, hallucinations, dementia or impulsive or compulsive behaviour. Individuals experiencing these symptoms may lack insight into what is happening, or fear disclosing them to health professionals, but can be prompted to do so with support from others, enabling them to access treatment and support.

It is also likely that the serious health impacts of loneliness will apply to people with Parkinson’s as to the rest of the population, making it even harder to live well with the condition, and placing people at risk of poor health related to loneliness.

All of these factors have a major impact on individual outcomes, but also carry financial costs. These include increased risk of hospital and care home admission, and increased use of non-emergency NHS care and social care services.

3. **Best practice and ideas that could be shared across Scotland, including examples of targeted support or initiatives (including housing, health, third sector)**

Parkinson’s UK supports over 40 local groups in Scotland, which offer friendship and a range of activities to people affected by Parkinson’s. Many people affected by Parkinson’s find it extremely helpful to meet with others in a similar situation, and sharing experiences can “normalise” some of the stigmatised and embarrassing symptoms so that people feel less isolated.

In addition, many of our local groups enable people to come together to sustain activities that can improve health and wellbeing. Exercise classes, dance classes and walking groups are very popular. They are particularly important in light of the growing evidence that exercise may help to slow the progression of Parkinson’s, but the social aspect is what enables people to maintain these activities.

In Dumfries, a “Loud Crowd” group brings people who have had an intervention to improve their speech together so that they can reinforce their learning and maintain the improvement over time. Some of our groups also offer regular activities like singing and art. In Lothian, local volunteers have developed a popular course for carers to help them to understand more about Parkinson’s and the issues that commonly arise when caring for someone with the condition.

Our free and confidential Information Support Worker provides one-to-one information and support to people with Parkinson’s, their families and carers. This may include benefits advice, emotional support and links to local and other services. Our information and support workers come across many people affected by Parkinson’s who are socially isolated, and and commonly refer these clients to their local Parkinson’s UK groups, the Parkinson’s UK online Forum or Buddying Service, and to services provided by other organisations.
Befriending services are very effective and popular, and people affected by Parkinson’s frequently ask to be put in touch with people to offer this kind of social support. However, there are huge gaps in provision throughout Scotland, with some areas having no befriending support, and befriending organisations in other areas reporting that their services are closed to new clients because of funding pressures. It is clear that existing befriending services are unable to meet demand.

4. Potential ideas for improvement and influencing policy
Parkinson’s UK believes that reducing the impact of social isolation will require action across a range of policy areas.

Social care has an important role in reducing social isolation. For people who live alone or are isolated within their family situation, and who find it difficult to go out, home care visits may be the only regular social contact that people have.

Parkinson’s UK believes that a shift in home care commissioning is needed, so that the importance of developing a human relationship between workers and clients is both recognised and accommodated within care packages. 15 minute care visits, and care that is solely task orientated, do not allow relationships to develop between clients and care workers. In addition, clients need consistency of carer workers in order to develop understanding, trust and social relationships.

For people who live in care homes, and are well enough to do so, care visits and trips are needed, along with activities that can enable residents to build relationships with each other.

Social support initiatives including befriending, buddying schemes, day centres and other social activities. All of these are provided by third sector organisations throughout Scotland, but are threatened by cuts to funding. The importance of this work as a preventative intervention which reduces dependence on statutory services needs to be recognised, so that cash-strapped local authorities are able to justify supporting these types of projects.

Accessible communities
Making communities more accessible to people with Parkinson’s could also have a major impact on social isolation by making it easier for people to be out and about in their communities, in terms of the physical environment and transport.

Parkinson’s UK believes that this should include:

- More places to adopt the dementia friendly communities model, both in terms of raising awareness of the issues that people with dementia face, but also creating built environments and services that are easier to use for people with dementia
• Buildings, pavements and public spaces that are accessible to wheelchair users and other disabled people. Parkinson’s UK is supporting efforts to introduce a Responsible Parking Bill to address these issues.

• Accessible public transport, including both vehicles and stations
  Access to blue badges for those with mobility needs. Blue badges are passported via the DLA/PIP benefits, which can only be applied for by people of working age. If an older person develops a condition like Parkinson’s that affects their mobility, or acquire other conditions or impairments, they have to complete a lengthy form to apply for a badge. This acts as a major barrier for some, who feel unable to complete the form. We are also aware of considerable local variation in whether older people with Parkinson’s are being awarded blue badges when they apply. We are aware that some people with very severe motor impairment are being turned down for badges by local authority assessors.

• Access to Motability vehicles. Parkinson’s UK believes that it’s essential that any transfer of disability benefits to Holyrood should include access to Motability or similar schemes for eligible people. We believe that extending the Motability scheme to disabled people who acquired their condition / impairment after the age of 65 should also be considered,

• Accessible public toilets, including “Changing Place” toilets that have space and equipment to enable them to be used comfortably by people with serious impairments, or who need to accompanied by a carer

Creating a society that welcomes difference, including older age and disability
Parkinson’s UK would like to see people living in a country that values older and disabled people, and is welcoming and understanding. We are concerned that the “scroungers” rhetoric around welfare benefits has legitimised negative attitudes to disabled people.

We believe that more should be done to address society’s fears around aging, frailty and dementia. We welcome the Scottish Government’s policy focus on older people as assets, but note that often this agenda focusses on older people in good health, which further marginalizes those whose health is not good. We believe that it is important not to “write off” those older people who need support. We want to make sure that the voices and experiences of older, frailer people – including disabled people and those with long term conditions and dementia - are heard by policy makers, and by society as a whole.

5. 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.

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