

LI 24

Ymchwiliad i unigrwydd ac unigedd

Inquiry into loneliness and isolation

Ymateb gan: Parkinson's UK

Response from: Parkinson's UK

Health Social Care and Sport Committee Loneliness and Isolation Inquiry Response from Parkinson's UK

Introduction and context

1. Parkinson's UK strongly welcomes the Committee's Inquiry on loneliness and isolation, which is a major issue for people living with Parkinson's in Wales. We would like to emphasise that loneliness and isolation can be a problem for people of any age.
2. Most people living with Parkinson's in Wales are aged over 50. 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.
3. Our response is informed by our work with some of the 7500 people in Wales who have Parkinson's and their unpaid carers, families and friends.
4. 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

1. Scale and Causes

5. Parkinson's UK believes that loneliness and isolation can occur in all types of settings, from remote and rural settings to urban areas and all points in between. Social isolation can affect people living 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. If someone cannot easily leave their house, they are at higher risk of being socially isolated whatever lies beyond their doors.
6. Rural areas that have a lack of public transport can increase social isolation, particularly when a person has had to give up their driving licence due to the progression of Parkinson's. Poor public transport can make it impossible to take up opportunities for social interaction.

7. Rural areas 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. Impact of isolation and loneliness

8. 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.
9. 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.
10. 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 isolated.
11. 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.
12. 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.

13. 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. Ways of addressing loneliness and isolation

14. Parkinson's UK supports around 30 local groups in Wales, 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.

15. 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 considering 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.

16. In Cardiff, the "Live Loud" group brings together people living with Parkinson's in an informal setting 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 day trips and additional projects to meet local needs are being developed with volunteers in our North and South Wales Local Development teams.

17. Our free and confidential Parkinson's Local Adviser service provides one-to-one information and support to people with Parkinson's, their families and carers across Wales. This may include benefits advice, emotional support and links to local and other services. Our Parkinson's Local Advisers come across many people affected by Parkinson's who are socially isolated, and commonly refer these clients to their local Parkinson's UK groups, the Parkinson's UK online forum, and to services provided by other organisations within their area.

18. Befriending services are very effective and popular, and people affected by Parkinson's often ask to be put in touch with people to offer this kind of social support. However, there are huge gaps in provision throughout Wales.

4. Policy Solutions

19. Parkinson's UK believes that reducing the impact of loneliness and isolation will require action across a range of policy areas.

20. **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.

21. Parkinson's UK believes that a shift in home care 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 to develop understanding, trust and social relationships.

22. 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.

23. **Social support initiatives including befriending, buddying schemes and other social activities.** 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 can justify supporting these types of projects where they are managed by third sector organisations.

24. Accessible communities

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

25. 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.
- Accessible public transport, including both vehicles and stations
- Accessible public toilets, including toilets that have space and equipment to enable them to be used comfortably by people with serious impairments, or who need to be accompanied by a carer

26. 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.

27. We believe that more should be done to address society's fears around aging, frailty and dementia. 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.

5. About Parkinson's

About 7500 people in Wales 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.

For further information, please contact Rachel Williams, Campaigns, Policy and Communications Officer for Parkinson's UK in Wales, [REDACTED], telephone [REDACTED].

¹ Karlsen KH, Tandberg E, Årslund D, Larsen JP (2000) Health related quality of life in Parkinson's disease: a prospective longitudinal study *J Neurol Neurosurg Psychiatry* 2000;**69**:584-589

² Forsaa, E. B., Larsen, J. P., Wentzel-Larsen, T., Herlofson, K. and Alves, G. (2008), Predictors and course of health-related quality of life in Parkinson's disease. *Mov. Disord.*, 23: 1420–1427.