

LI 21

Ymchwiliad i unigrwydd ac unigedd

Inquiry into loneliness and isolation

Ymateb gan: MS Society

Response from: MS Society



National Assembly for Wales Health, Social Care and Sport Committee inquiry into loneliness and isolation – Response from MS Society Cymru

Summary

MS Society Cymru welcomes the opportunity to provide feedback on the National Assembly for Wales' Health, Social Care and Sport Committee inquiry into loneliness and isolation.

Multiple Sclerosis (MS) is an incurable neurological condition, which affects approximately 4,900 people in Wales, and more than 100,000 people in the UK.

Around 85% of people with MS are diagnosed with Relapsing-Remitting MS. People with this kind of MS have distinct attacks of symptoms which then fade away either partially or completely. Many go on to have secondary progressive MS. It means they have a sustained build-up of disability, completely independent of any relapses. Primary progressive MS affects about 10 to 15% of people diagnosed with MS. Symptoms gradually get worse over time, rather than appearing suddenly.

1. Social isolation and loneliness among people living with MS

- 1.1. Social isolation and loneliness is a significant issue for people of all ages who are living with MS in Wales. In particular, people living with more progressive forms of MS have reported feelings of isolation as a consequence of their condition.
- 1.2. Social isolation among people living with MS can occur in all types of settings, from rural areas to larger urban conurbations. If someone cannot easily leave their house, they are at higher risk of being socially isolated whatever lies beyond their doors.
- 1.3. In 2014, the MS Society UK in collaboration with Plymouth University conducted research on social isolation among people severely affected by MS.ⁱ This study found;
- 1.4. Physical restrictions were the most commonly mentioned causes for social isolation. Participants described the difficulties they face in trying to get out and make or maintain contact;
- 1.5. "...the adventurous side of my spirit that used to take me out and about... because of various difficulties and physical constraints have made me isolated, 90% of what I do is in my own home environment".
- 1.6. "I'm in my home on my own for most of the week, and I've started to really struggle and feel unbearably lonely. I'm not able to get outside of my home on my own and only have 4 hours care a week".

- 1.7. For someone living with MS, the ability to leave their home and move independently is a complex undertaking. Whilst mobility aids can help to facilitate people living with MS to get around, many who use them report that they are often difficult to use and generally still require assistance from others.
- 1.8. Difficulties encountered with pavements, accessing buildings such as shop entrances and general accessibility issues etc. prevents people living with MS from accessing the outside world. Consequently, people living with MS are disabled by virtue of the fact that the built environment prevents them from accessing it and as a result are isolated in their own homes.
- 1.9. Whilst social isolation and loneliness affects people living with MS regardless of where they live, the issue is particularly compounded for those who live in rural areas.
- 1.10. A lack of accessible public transport substantively increases social isolation for people living with MS in rural areas. This is especially pertinent where a person has had to give up their driving licence or mobility vehicle as in the case for many who are going through the Personal Independence Payment assessment process and awaiting the outcome of an appeal.
- 1.11. Research conducted by the MS Society UK estimates that 1,489 people living with MS have had their mobility support downgraded since PIP started to replace DLA and up to 10,000 more people living with MS across the UK could lose out by the time PIP is fully rolled out. ⁱⁱ
- 1.12. Poor public transport can make it impossible to take up opportunities for social interaction. In addition, rural communities may also have fewer local opportunities for social interaction.
- 1.13. Another factor leading to isolation of people living with MS is toileting and incontinence. For many, self-catheterisation limits the amount of time for excursions away from home and can make even the shortest of car journeys become difficult.
- 1.14. Notwithstanding the lack of available public toilets, for many people who do try to find their way to a public toilet, many of those which purport to be 'accessible' are not fit for purpose.
- 1.15. For example, many people living with MS who are wheelchair users consistently report difficulties with being unable to manoeuvre their wheelchairs into the required space; sanitary/nappy bins and other furniture are frequently placed inappropriately and the accessible toilets being used as store cupboards.
- 1.16. An example of the difficulties encountered by people living with MS was highlighted by one of the participants in the MS Society study into isolation. The woman cannot easily change her shoes and tends to be in slippers at home which she can slip on and off. This is not something she can do with ease with other shoes. To perform the 'pirouette' as she calls it to use a toilet, she needs to take off her slippers and this is possible at home. However as she says, "I would go up to the shops but I don't really want to out in my slippers. I can't go to the toilet. I cannot put ordinary shoes on as I can't get them off to do my pirouette in them". As she is unable to put her shoes on and off by herself, she is unable to go to the toilet on her own and is therefore trapped within her own home.
- 1.17. An MS Society UK survey into the discrimination of people living with MS conducted in 2016 revealed that almost half (45%) of people with MS have experienced mistreatment or stigma because of their symptoms. ⁱⁱⁱ

- 1.18. The most common experience is being accused of being drunk because they were having trouble walking (49%). While, 47% say they have received comments that they are exaggerating the extent of their MS because they 'look so well', 35% have been accused of wrongly parking in a disabled bay because they didn't appear disabled. Three quarters (73%) of people with MS say that living with the condition is more difficult when people treat them badly or stigmatise them because of their condition.
- 1.19. MS is a condition that is already unpredictable and challenging to live with and this stigma and misunderstanding is making life even harder for many of the 4,900 people living with the condition in Wales.
- 1.20. The survey results also showed that understanding family and friends can make a positive difference to those living with MS. Of those people living with MS who said they were supported during a difficult incident, 63% received help from a partner, 40% from immediate family and 34% from friends.
- 1.21. "MS means I have a poor sense of balance, and one morning I fell over in a busy marketplace. As I struggled to pull myself back up by grabbing onto wall, a woman walking past pulled her child away from me and said loudly "Disgusting drunk!" I was too stunned and upset to respond. My family and friends are a shield for me against misunderstandings and discrimination".
- 1.22. However, unpaid carers of people living with MS are also at high risk of social isolation. People with more progressed forms of the condition 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 MS experience very high levels of stress and other mental health issues which both contribute to and can be exacerbated by social isolation.
2. The impact of social isolation for people living with and affected by MS is significant. Studies have suggested that depression is among the most common symptoms of MS and it is more common among people with MS than in the general population.
- 2.1. "I've started to feel really anxious and scared and I can't get past these feelings. I've developed bad depression and I've lost contact with friends".

3. Addressing the problem

- 3.1. Access to appropriate professionals is a key factor in addressing social isolation for people living with MS.
- 3.2. People living with the condition rely on the specialist expertise from a whole range of professionals including physiotherapists, occupational therapists, speech and language therapists, orthoptists, psychologists, continence and rehabilitation specialists who may be needed at different times to assess and treat symptoms effectively, and to prevent secondary complications from developing as a result.
- 3.3. The MS Society UK published findings from the 2016 My MS My Needs survey which showed that access to MS specialist services across Wales is patchy.^{iv}
- 3.4. In 2017, MS Society Cymru will be launching a Big Lottery Funded project which will support 1,300 people living with and affected by MS in Wales. This project will offer support on a range of issues including access to social care, treatments, employment rights, mindfulness and welfare support. Such a holistic approach will go some way in combatting the difficulties faced by people living with MS and in conjunction with the local

activities organised by MS groups, will over time, reduce the prevalence of loneliness and social isolation among those who access the services.

- 3.5. However, reducing the impact of social isolation for everyone living with and affected by MS in Wales requires urgent action across a range of policy areas.
- 3.6. In addition to accessing appropriate health professionals identified above, social care has a vital role in reducing social isolation and loneliness. 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.
- 3.7. Greater access to direct payments would allow people living with MS to use the funds to do activities that are important to them, rather than having to fit into more traditional and increasingly limited service options.
- 3.8. Making communities more physically accessible to people living with MS would also have a significant impact on preventing and alleviating social isolation by making it easier for people to be out and about.
- 3.9. Challenging the stigma attached to disability especially hidden disability would also go a long way in creating a society that welcomes difference and enables people to venture out of their homes without fear of mistreatment.
- 3.10. Implementation of the Social Services and Well-being (Wales) and Future Generations Acts should ensure that commissioners of services have due regard to include initiatives to prevent and alleviate isolation and loneliness.
- 3.11. Isolation and loneliness can affect people living with MS in so many different ways. In order for the issues identified above to be fully addressed, the Welsh Government must also ensure that isolation and loneliness is embedded in all of its work.
- 3.12. The Framework for Action on Independent Living examines the barriers to equality and inclusion faced by disabled people in Wales, and the action needed to address them. It was developed following extensive engagement and consultation with disabled people across Wales and has a government-wide and cross-generational focus on barriers and actions for improvement.
- 3.13. The Framework supports the Welsh Government's Strategic Equality Plan and Objectives across portfolios and provides a detailed programme of action to tackle barriers to support disabled people so that they can live independently and exercise choice and control in their daily lives.
- 3.14. Given the extent of isolation and loneliness among people living with MS in Wales, it is clear that much more needs to be done to promote the 'inclusive and enabling society' as envisaged by the Framework. To this end, MS Society Cymru urges the Health, Social Care and Sport Committee to instruct the Welsh Government to ensure that the Framework for Action on Independent Living is fully adopted across all Welsh Government portfolios and by local delivery partners and stakeholders.

Contact

Fiona McDonald, Policy, Press & Campaigns Manager
MS Society Cymru, Temple Court, Cardiff, CF11 9HA

Tel: [REDACTED] / [REDACTED]

ⁱ Robens et al, 2014. Social isolation amongst severely impaired people with multiple sclerosis (MS): choice, control and identity. Available here: [file:///C:/Users/fmcdonald/Downloads/Robens%20et%20al%20Social%20Isolation%20in%20people%20with%20MS%202014%20\(2\).pdf](file:///C:/Users/fmcdonald/Downloads/Robens%20et%20al%20Social%20Isolation%20in%20people%20with%20MS%202014%20(2).pdf)

ⁱⁱ MS Society 2016 <https://www.mssociety.org.uk/ms-news/2016/08/one-10-people-ms-could-face-disability-benefit-cuts>

-
- ⁱⁱⁱ MS Society 2016 <https://www.mssociety.org.uk/ms-news/2016/09/half-people-ms-have-faced-%e2%80%98unacceptable%e2%80%99-mistreatment>
- ^{iv} MS Society, 2016. My MS My Needs 2016: Access to treatment and health care. Technical Report. Available here: <https://www.mssociety.org.uk/sites/default/files/MMMN%202016%20Technical%20report.pdf>