

# Experiences and Needs for Peer Support among People Affected by Multiple Sclerosis in Ireland

## Survey summary

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### Background and Aims

People living with multiple sclerosis (PwMS) and those who care for PwMS are at risk of experiencing low levels of wellbeing. This could be due to the various challenges presented by multiple sclerosis (MS) symptoms and treatment, uncertainties about the future, socioeconomic pressures, or other aspects of life with MS.

One way to improve wellbeing in MS is through the provision of **peer support**. Peer support can take many forms, including opportunities for PwMS (or MS caregivers) to meet face-to-face or in online settings. Peers can provide information and emotional support to each other, as well as a range of other benefits. Yet, little research has investigated the needs and experiences of peer support among those affected by MS in an Irish context. This study aimed to explore this issue in depth, specifically by establishing the levels of need for and engagement in both online and in-person peer support among PwMS and MS caregivers in Ireland.

### Methodology

An online survey was designed with the help of public and patient involvement from 9 PwMS and 3 MS caregivers, with responses collected in February-March, 2024. As well as questions relating to participants' preferences for and engagement with peer support, the survey included a number of questions which asked people about their background, experiences of loneliness, social support and wellbeing.

### Participant background and health or care characteristics

218 PwMS and 27 MS caregivers took part in the survey, with an average age of 49.32 years and 49.41 years, respectively. The sample was predominantly female (more than 75% in both groups) and almost entirely Caucasian. PwMS were evenly split between those living in rural (48%) and urban (52%) areas, while MS caregivers were predominantly from urban (72%) areas.

PwMS had been living with MS for an average of 13 years, with the majority (64.7%) having Relapsing-Remitting MS, and a further 27.5% having either secondary or progressive MS. While most (57.86%) of the sample were

able to walk unaided, about a third experienced considerable difficulties, and relied on a walking aid or wheelchair to move around, for 25 feet in 20 seconds.

Most of the MS caregivers were spouses or partners (63%) to their care recipient. Overall, those providing care did so for an average of 82 hours a week, with some providing 24-hour care, seven days a week. Most reported at least some burden from caregiving.

## **Experiences of loneliness, social support & wellbeing**

Experiences of loneliness varied in PwMS. While about a third had a low levels of loneliness, a considerable proportion experienced high levels of loneliness: 17.4% reported high, and 45% reported moderate levels, while the remainder (33.9%) reported low levels of loneliness. In contrast, the majority (51.9%) of caregivers reported low levels of loneliness, with the remainder reporting moderate (3.7%) or high levels (25.9%). This means that PwMS felt lonelier than caregivers in this sample. PwMS living in rural areas and those with progressive MS reported higher loneliness scores. Among caregivers, siblings and caregivers reporting moderate caregiving burden had higher loneliness scores.

Levels of social support, which refers to social connections in a person's life and how they might be emotionally available and be present to offer practical assistance when needed, were also lower in PwMS. To contextualise social support, an example might be how easy it is for PwMS to get practical help from social contacts or people known to them including neighbours. Additionally, PwMS reported lower levels of social support compared to MS caregivers. Those from rural areas and those reporting Secondary Progressive Multiple Sclerosis were more likely to report lower social support. Among MS caregivers, partners reported poorer social support compared to siblings and parents.

Taken together, this suggest that PwMS are at risk of social isolation

About wellbeing, both PwMS and MS caregivers reported lower than average levels of wellbeing, although compared to PwMS, MS caregivers had higher levels of wellbeing. PwMS are therefore at higher risk of depression.

## **Experiences of and engagement with peer support**

### **In-person peer support engagement**

The most common types of in-person support availed of by PwMS were i) specialised interventions of services such as Yoga, ii) social activities such as coffee mornings, and iii) formal meetings or seminars, all organised by MS Ireland. Caregivers engaged in support from MS community workers, other carers, and people at MS events.

The majority of PwMS and MS caregivers surveyed had little or no in-person engagement with peers; 66% of PwMS reported never or rarely engaging in in-person peer support, while 63% of MS caregivers reported never doing so.

Those who never engaged in in-person peer support reported multiple factors that hindered their engagement. In PwMS, barriers to engagement included no information on available peer supports, limiting attitudes such as fear of seeing their future reflected in other people with progressive MS types, and factors limiting access to available support ranging from time to location amongst others. MS caregivers also described a general lack of information. In their views these included a lack of general information about peer support opportunities from their care recipients MS healthcare providers, and local opportunities including not knowing other MS carers. Although, one provided knowledge of a social mediated caregivers support group, but they were not on social media.

This suggests a potential information and awareness gap on available supports, while other ways to improve or create more accessible supports can be explored.

## Online peer support engagement

The most common types of online peer support PwMS availed of were i) MS Ireland specialised interventions such as physiotherapy, ii) MS Ireland information and learning supports, and iii) personal social media platforms such as Facebook. Caregivers, on the other hand, engaged with local and international websites, Facebook, and messaging services.

A greater proportion of PwMS had engaged in online peer support compared to caregivers in this survey; 28% of PwMS had never engaged in online peer support, while the majority (44%) of caregivers never engaged in online peer support.

PwMS offered several reasons for their non-engagement with online peer support. Many respondents saw no need for peer support. Other reasons included being in denial about MS and seeing no benefits in participation. Reasons for MS caregivers' non-engagement with online peer support included a lack of information about available options, a dislike of online activities, or being shy.

These findings suggest information and awareness gaps of available online peer supports and a need to address attitudes that might limit engagement with peers.

## Peer support need

A significant proportion of PwMS need peer support. Of those that expressed need, about a third (33%) reported that these were met, while 22% reported an unmet need for peer support. The majority (44%) of caregivers had an unmet need for peer support, and only 4% had peer support needs that were being met. 33% of PwMS and 22% of caregivers had no peer support needs.

## Peer support benefits

Both PwMS and caregivers found peer support beneficial, regardless of its delivery format, as exemplified in the quotes below.

***'I can only see benefits – it would be wonderful to have peer support, someone else who understands the challenges and stresses of the condition and the care needed for a person with the condition'***

“

**50-year-old caregiver**

***'(Its benefits are) enabling more informed decisions about lifestyle, medication. (Also) emotional support for anxiety about the future and use of medication'***

“

**48-year-old living 6 years with MS**

Further, 56% of PwMS and 44% of MS caregivers agreed that peers were useful sources of information. Also, 48% of PwMS agreed that PwMS were a useful source of emotional support (no caregiver responded to this question).

Overall, the findings indicate that PwMS and their caregivers find peer support beneficial.

## Peer support preferences

Informal peer support, such as meetings or coffee mornings with other PwMS/ MS caregivers, was preferred by participants, who also expressed a preference for having more structured meetings, delivery online, or via social media. Caregivers also expressed preferences for meeting with carers of similar neurological conditions.

In terms of its composition, 44% of caregivers and 48% of PwMS agreed that peer support groups should be composed of peers with similar disability levels/ levels of care recipients. Ideally, they felt that these should be in groups of about 7 or 8 people.

## Key conclusions

1. PwMS are at risk of loneliness and low psychological wellbeing; peer support may offer one way to tackle this
2. While not all PwMS experience needs for peer support, quite a number do – there is a substantial cohort of PwMS reporting that they would benefit from peer support, suggesting that this is a common unmet need.
3. One key way to address barriers in current opportunities might be creating peer support options for people of different health statuses (abilities) and ages, while increasing awareness of support in general.
4. Although only a small number of caregivers participated in this survey, findings suggest that while peer support was desired, there were even fewer opportunities for peer support in this group.

## Key recommendations

 **Increase awareness of peer support opportunities among PwMS and MS Caregivers**

 **Create peer support options for people of different health statuses (abilities)**

 **Increase flexibility in the options for peer support, for example, providing opportunities for peers to meet up at different times**

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