



Community Worker Business Proposal

May 2025

The Multiple Sclerosis Society of Ireland



Contents

Executive Summary	4
MS Ireland's Model of Care	5
Challenges facing People Living with MS	6-8
Proposal	8-9
Community Worker Service Impact	10-11
Conclusion	12
Case Study	12-13
MS Ireland Regional Offices	14

Executive Summary

As the national organisation responsible for the provision of services to people with Multiple Sclerosis (PwMS), the Multiple Sclerosis Society of Ireland (MS Ireland) is seeking €72,997.56 (€65,674.82 salary and Employers PRSI €7,322.74) to provide one full-time Community Worker covering counties Sligo and Leitrim. MS Ireland currently provides a Community Work service in all counties in the Republic of Ireland, except for Sligo and Leitrim. The primary activity of the Community Worker Service is casework for people with MS, offering crucial individual and family support, advocacy, and referrals to other services. In addition to casework services PwMS will have access to a suite of other services including respite, physiotherapy, fatigue management and other evidence-based programmes. In Sligo/Leitrim, where a significant number of PwMS are registered with MS Ireland, there is no dedicated Community Worker, leaving only limited phone-based support available. It is estimated based on CSO population data, that there are over 300 people living with MS in Sligo and Leitrim, 122 of those are already known to MS Ireland's services.

The Community Worker service will enable:

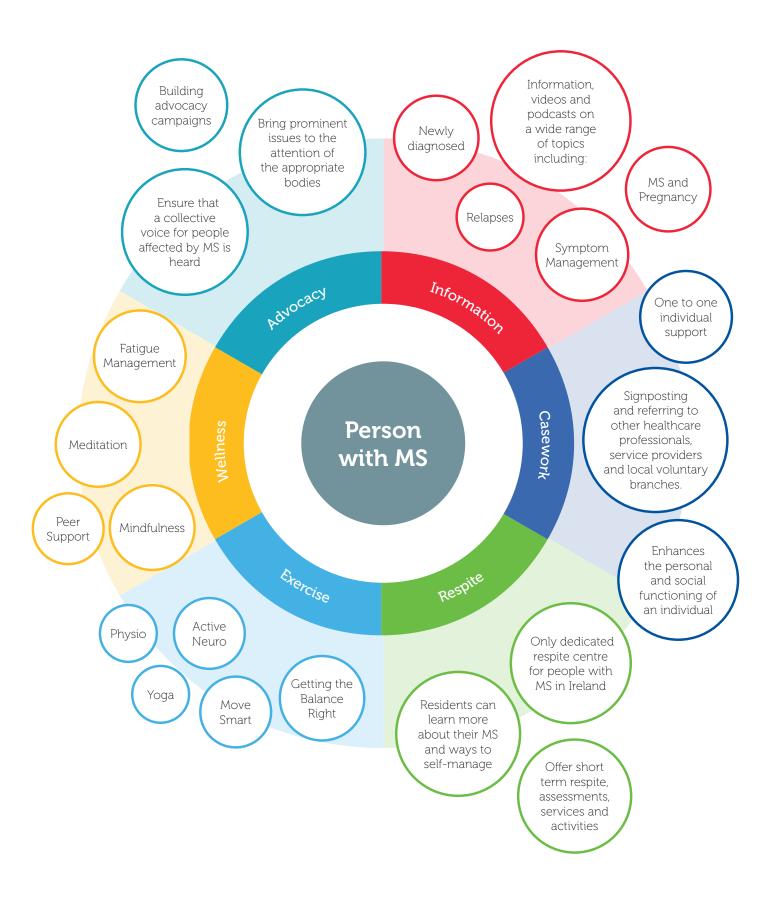
- Comprehensive casework support for PwMS and their families, addressing needs from diagnosis through the progression of the disease.
- **Improved access to early intervention** services, which are proven to result in better outcomes for PwMS.
- Reduced pressure on other healthcare professionals, including G.P's, Case Managers, Occupational Therapists, and Social Workers, as the Community Worker will manage tasks more suited to this specialised role.
- Stronger collaboration with HSE and statutory services in Sligo/Leitrim, in line with the Sláintecare objective of delivering integrated, accessible, and locally planned services.
- Enhanced visibility and impact of MS Ireland's services in the Northwest Region.
- Opportunity to avail of MS Ireland's other services e.g. respite, physiotherapy, social supports etc.

Multiple Sclerosis (MS) is a complex lifelong neurological condition that requires ongoing support and intervention for those affected. No two people with MS experience MS in the same way. The Community Worker will provide tailored support in areas such as symptom management, employment, housing, education, and emotional well-being. They will advocate on behalf of PwMS, make necessary referrals, and offer holistic, solution-focused support that addresses the physical, mental, and emotional needs of PwMS. The proposed extension of services aligns with Sláintecare's vision of providing the right care in the right place at the right time.

There are 19 MS Ireland Community Workers (16 whole time equivalents) working across the rest of the country. In 2024, 2538 people with MS received a 1:1 casework service. In 2024, the number of new referrals to the Community Worker service increased by 26%. Prevalence rates for MS are rising globally and Ireland is no exception. The reasons for increased prevalence are multifactorial and likely include better diagnostic tools, rising incidence of autoimmune conditions and environmental factors.

The HSE Capacity Review, Sláintecare Report and Neurorehabilitation Strategy's underlying principle is that services must be integrated, proactive and community-based with an emphasis on planned models of care. MS Ireland's Community Worker Service, along with a suite of other services, delivers this model of care.

MS Ireland's Model of Care



Challenges facing People Living with MS

In 2021, MS Ireland in conjunction with the University of Maynooth, conducted a review of its casework service. A central part of this project was to seek the views of both Community Workers and PwMS on their experience of casework. PwMS cited the need for information, coordination of care, and emotional or psychological support. Our results found that no two people with MS are the same, and so a tailored assessment and person centred plan is required for all people accessing the service. Community Workers are well placed to provide this service and support.

The 2018 HSE Disability Capacity Review states that Community Workers are listed as one of the most used MDT services by adults with disabilities.

"Where these roles are available, people with disabilities can be enabled to access mainstream activities and services, slowing down or reducing the uptake of more traditional disability services"

Needs experienced by People with MS:



Results from the review suggest that community workers help to meet needs of PwMS in four main ways:



Frequent issues identified by PwMS in Sligo/Leitrim include:

- 1. It is frequently reported to MS Ireland that following a diagnosis, PwMS living in Sligo/Leitrim are left with no one to speak to. MS Ireland provides limited phone support to PwMS in Sligo/Leitrim where possible through our Casework Service in Donegal and the MS Ireland Information Line. It should be noted that, according to MS Ireland's MyMSMyNeeds study, conducted in 2023, 14% of PwMS live alone. Early intervention is key to better outcomes for PwMS.
- 2. At the time of diagnosis, a PwMS is left with many questions and decisions regarding their future. The first of these decisions may be choosing a disease modifying therapy. According to MS Ireland's MyMSMyNeeds study, only 63% reported having received enough information about DMTs from healthcare professionals indicating a clear need for greater provision of support in this area.
- 3. At this time, applications for medical cards, GP cards, Long-Term Illness Scheme are necessary. It is frequently reported to MS Ireland, how overwhelming and complex a PwMS finds this process at time of diagnosis, support is required.
- 4. It is frequently reported to MS Ireland that phone support is not enough. A barrier to providing effective support is that as the staff receiving calls are not based in Sligo/Leitrim and are limited in the information they can provide. A Community Worker based locally would ensure appropriate referrals and engagement with necessary service providers.
- 5. Remaining in employment is a challenge frequently experienced by PwMS. Often people

from Sligo/Leitrim contact the information line requiring support regarding reasonable accommodations in employment. Phone support is limited, while a Community Worker will assist with navigating those conversations with employers. Unfortunately, high unemployment rates are experienced amongst people with MS, it is important that every effort is made to assist in maintaining PwMS in employment.

6. Accessing available financial supports is a huge challenge for a person with MS. Lack of awareness of financial supports and the application process often posing a barrier. A Community Worker can assist in exploring all options and assist with completion of applications where necessary, to ensure equity across all counties.

Proposal

According to the Long-Term Illness Scheme, in 2023 10,697 people were accessing medications for MS in Ireland. This figure excludes those on certain therapies and those not in receipt of medication. It is estimated that over 300 of those people diagnosed with MS are living in Sligo/Leitrim. MS Ireland is seeking €72,997.56 (€65,674.82 salary and PRSI €7322.74) to provide one full time Community Worker covering counties Sligo and Leitrim. MS Ireland currently provides a Community Work service in all counties in the Republic of Ireland, except for Sligo and Leitrim. MS Ireland has a long history of providing a casework service to people with MS across the country, it is necessary to extend the service into Sligo/Leitrim.

Benefits of the proposal include:

- Comprehensive casework support for PwMS and their families, addressing needs from diagnosis through the progression of the disease.
- Improved access to early intervention services, which are proven to result in better outcomes for PwMS.
- Reduced pressure on other healthcare professionals, including G.P's, Case Managers,
 Occupational Therapists, and Social Workers, as the Community Worker will manage tasks more suited to this specialised role.
- Stronger collaboration with HSE and statutory services in Sligo/Leitrim, in line with the Sláintecare objective of delivering integrated, accessible, and locally planned services.
- Enhanced visibility and impact of MS Ireland's services in the Northwest Region.
- A clear referral pathway to MS Ireland's other evidence based programmes i.e. physiotherapy, fatigue management etc.
- As already stated, the HSE Capacity Review, Sláintecare Report and Neurorehabilitation Strategy's underlying principle is that services must be integrated, proactive and community-based with an emphasis on planned models of care. MS Ireland's Community Worker Service, along with a suite of other services, delivers this model of care.



Sláintecare defines integrated care as:

Healthcare delivered at the lowest appropriate level of complexity through a health service that is well organised and managed to enable comprehensive care pathways that patients can easily access and service providers can easily deliver. This is a service in which communication and information support positive decision-making, governance and accountability; where patients' needs come first in driving safety, quality and the coordination of care.



It is worth noting that Community Workers are already working collaboratively and complementing the roles of HSE Social Work and Case Managers around the country. As a result many cases don't reach a Social Work or Case Management referral. The Community Worker undertakes the co-ordination, leaning on Social Work or Case Management where required.

This is of particular relevance given the social recruitment crisis, and in the context of the Irish Association of Social Work advise that only 250 Social Workers qualify per year when 500 are needed.

Community Worker Service Impact



The Community Worker provides a service through all stages of the disease, from time of diagnosis through changing needs as the disease progresses. It is understandable that following a diagnosis of Multiple Sclerosis (MS) that a PwMS can often be left with many questions or concerns about symptoms, treatment options and how other aspects of their life might be affected by the diagnosis. The Community Worker will ensure a PwMS has timely, up to date and accurate information. The PwMS will be assisted by the Community Worker to navigate the health care system. The Community Worker will advocate on behalf of the PwMS and will make referrals where appropriate. Year on year, the top presenting issues for PwMS which the Community Worker Team assists with are –



Access to Healthcare



Emotional Support



Financial Welfare



Home Support and PA

Case Work involves responding to the contact made by the PwMS and providing one to one individual support to both the PwMS and their families (where appropriate). It is a process of enhancing the personal and social functioning of an individual through an assessment of need, working with the individual and family to enhance problem solving and coping capacities. It involves making necessary referrals to other agencies for resources and services to promote

the well-being of the PwMS. It is important that the PwMS directs all our individual support work, and we conduct this work in a confidential and sensitive manner. Regional Community Workers can meet people in their home, in the community, talk over the phone or on Zoom - wherever is convenient to them.

Becoming a carer for a family member or loved one is often unplanned. In the caring role, personal relationships with partners, parents and children can be affected. The Community Worker can help to address the challenges experienced by family/carer and identify management strategies in collaboration with the PwMS and other relevant health care professionals. Strategies include the provision of information regarding MS, provision of information regarding financial and emotional supports and ensuring that other appropriate health care providers and services are involved.

The model of practice used by MS Ireland is best described as a solution-focused model. The solution-focused model is goal-directed and is based on searching for solutions.

Once the PwMS becomes a client of the Community Worker Service, they have access to regular information and a range of other services provided by MS Ireland. Respite is available at MS Ireland's Care Centre in Rathgar, Dublin, also available are physiotherapy and exercise related activities, fatigue management programmes, information events, advocacy services, peer support and where available financial assistance from their local branch.



Scan the QR Code

Discover the positive impact of MS Ireland's Regional Services as our community workers share their experiences and discuss their vital roles.

Conclusion

The addition of a full time Community Worker post in Sligo/Leitrim represents a vital step towards equitable, high-quality support for PwMS in the Northwest Region. This role will provide essential casework services that address the unique challenges faced by PwMS and their families, including emotional support, advocacy, and access to resources. Extending the established Community Work model to Sligo/Leitrim will not only fill a significant service gap but also contribute to integrated care delivery in line with Sláintecare principles.

By investing in this additional post, MS Ireland will ensure that PwMS in Sligo/Leitrim have access to the same level of care and support as those across the rest of the country, improving outcomes and quality of life. This proposal reflects MS Ireland's commitment to empowering individuals, strengthening communities, and enhancing the delivery of MS services in Ireland.

Mary's Story

When I was diagnosed with Multiple Sclerosis in 2006, there was no dedicated Community Worker in Sligo. Almost two decades later, the situation remains unchanged. Upon diagnosis, I was provided with medication options by my neurologist and left to navigate the rest on my own. The MS nurse gave me advice on how to take the medication, but beyond that, there was no structured support system.

I had no access to information about how to connect with others living with MS, no guidance on what my future could look like if I had to stop working, and no knowledge of financial supports available. There was no direction on accessing home care should I require it, nor any mention of MS Ireland and the resources they offer.



The absence of a community worker service in Sligo and Leitrim has long been a gap in services for people with MS.

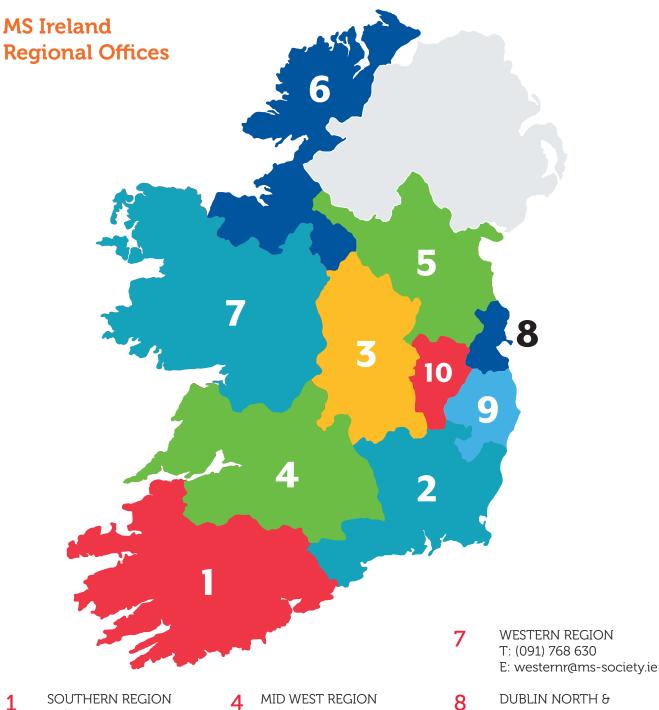
I recently spoke with a young woman diagnosed just a few months ago, and she reminded me of myself at that stage—fearful and completely unaware of where to turn for information and support. Another newly diagnosed young woman from Sligo had to join Donegal's MS online meetings simply to meet others with MS, as she knew no one in her local area living with the condition. Newly diagnosed individuals need to know that life with MS can still be full and meaningful.

Due to the lack of support in Sligo, I reached out to MS Ireland. I joined meetings online each month, where I was able to connect with others in similar situations. Through these meetings, I not only found community but also received essential advice on managing life with MS. Beyond emotional and social support, MS Ireland provided me with crucial practical assistance. I was helped to obtain my Primary Medical Certificate by the MS Ireland team, guiding me through the necessary paperwork, explaining the process, and preparing me for my meeting with the medical doctor. Without this help, I would not have been able to secure my certificate. During the COVID-19 pandemic, MS Ireland also directed me to online exercise classes, which I continue to benefit from today. These classes have been vital in helping me maintain mobility and overall well-being.

While I have been fortunate to receive support from MS Ireland, the support is limited, simply because there isn't a local Community Worker. If my MS worsens, I will have no Community Worker in Sligo to assist me, and that uncertainty is deeply stressful.

It is unacceptable that PwMS in Sligo and Leitrim still do not have access to a dedicated community worker. It took me years to discover the supports that exist, but newly diagnosed individuals should not have to wait that long. A Community Worker in Sligo/Leitrim would ensure that PwMS receive timely guidance, resources, and emotional support, helping them navigate life with MS from the moment of diagnosis.

MS Ireland's ask is for additional funding in 2026 to recruit a full time Community Worker post at a total cost of €72,997.56 (€65,674.82 salary and PRSI €7,322.74)



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