



Respite Centre Business Case

The Multiple Sclerosis Society of Ireland

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Respite Centre Business Case



Executive Summary

As the organisation responsible for provision of the only national respite centre catering for the needs of people with Multiple Sclerosis and other neurological conditions, MS Ireland is seeking an additional €627,000 to offer 1,248 additional bed nights per year. Located on Bushy Park Road, Rathgar, Dublin 6, the National MS Respite Centre, with 12 beds, currently runs at reduced capacity, closing every second weekend.

The additional funding would provide an additional 12 weeks of respite per year. An additional €627,000 will increase bed availability and provide additional high quality respite care from experienced nursing and healthcare staff, which will not only benefit those using our service and their families but will also assist the HSE in alleviating pressure on an already inadequate number of respite beds for people with MS and other neurological conditions.

Multiple Sclerosis (MS) is recognised as the most common debilitating neurological condition among young adults and is registered as the largest cohort seeking HSE services (NASS 2020). The number of people with MS registered on the Long-Term Illness Scheme in 2022 was 10,387.

In 2022, the respite centre welcomed people with MS, Parkinson's, Ataxia, Stroke, Spinal Injuries, ME and Muscular Dystrophy.

Respite care is consistently referred to as a key formal intervention to alleviate the stress of caring and is identified in literature as critical to supporting carers.

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 Respite Service, along with a suite of other services, delivers this model of care.

MS Ireland's Model of Care





The Irish State is estimated to save €20 billion on an annual basis due to the 500,000 family carers that provide unpaid care each day to those living with disability or illness.

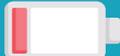
Care Alliance 2023

Challenges facing Irish Society in the provision of respite include:

1. Carers have provided increased levels of care with less support and respite since the Covid-19 pandemic. This impacts the wellbeing of carers and persons requiring care. There is significant human cost for those affected by the reduction and closure of respite services, and the ongoing acute levels of unmet needs must be considered.
2. According to the Department of Health Service Capacity Review 2018, it is anticipated that the number of people requiring Home Care Packages will increase by 10,000 by the end of 2032. This increase in demand will be driven mainly by the over 75 age cohort. Increased demand for home support will impact the need for increased respite services, given the current home support crisis that is happening across the country. Home Support packages, which are not filled due to recruitment, place a greater burden on the family/informal carer. **In 2022, MS Ireland statistics show that home support issues accounted for 29% of issues raised with the MS Ireland Case Work Service.**
3. The Disability Capacity Review highlights that the requirement for residential care (nursing homes) is set to grow by 39% by 2032. PwMS under 65 are currently offered respite in nursing homes, where more appropriate facilities are not available. This is unacceptable to MS Ireland. However, accessing a nursing home respite bed has become challenging, it is imperative that funding for appropriate respite services is addressed. **In 2022, MS Ireland statistics demonstrate that 23% of issues raised with the Case Work service were regarding respite.**
4. The consequence of a failure to address identified current and future need is likely to be increased demand for crisis unplanned interventions, at significantly higher unit cost than planned services. HSE Activity Statistics inform us that at the end of September 2022, 68 emergency places had been provided and 434 home respite supports for emergency cases were put in place.

Caregivers spend an increasing number of hours each week providing care

Of these caregivers:

 **64%** are emotionally drained

 **32%** experience depression

 **22%** have lost a job due to caregiving responsibilities

(National Multiple Sclerosis Society 2021)

Introduction to MS Ireland's Respite Service



MS Ireland has a long history of delivering specialist respite and has consistently demonstrated its ability to provide high quality respite care which is evident in our registration and monitoring inspections with the Health Information and Quality Authority (HIQA).

MS Ireland **has robust clinical and organisational governance systems.** The respite centre is managed by the Clinical Nurse Manager who reports to the Director of Services. The Clinical Nurse Manager leads a team of nursing staff, healthcare assistants, one physiotherapist and support staff (approximately 30 staff).

In addition, the respite centre is home to a long-standing Community Employment Scheme. The scheme is approved for 26 participants and plays a vital role in the day-to-day running of the respite centre. The complement of staff ensures that the respite centre can meet the needs of residents in the low to high care dependency level categories. The respite centre's staff team

bring expertise and specialist knowledge of MS that cannot be provided elsewhere. Due to the returning nature of service users to the respite service, staff and service users build a relationship based on confidence and trust in the care delivered and understanding of their complex condition.

The respite centre is a purpose-built facility owned and maintained by MS Ireland with the sole aim of providing respite to people living with MS and other neurological conditions. Unlike many other respite services which are rented, MS Ireland invests annually in maintaining its high standards for those that use the service.

The respite centre has 12 ensuite accessible bedrooms and has capacity for approximately 400 admissions annually. Admissions can be for 5, 7 or 12 nights depending on individual circumstances and requests. The service delivers planned, age and need appropriate respite breaks and prides itself on its ability to deliver respite without cancellation.

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Referrals or enquiries for admission come from hospitals, community-based professionals or from people directly affected by MS. MS Ireland has a network of Community Workers (19) based around the country aligned with the Health Services Executive (HSE) Community Health Organisations (CHOs).

The Community Workers will assist PwMS with the referral process, ensuring **accessibility** to services. Pre-assessment will be completed to ensure that all necessary equipment, knowledge and expertise are available to meet the resident's needs. The respite centre can accommodate a maximum of six high care dependency residents at any one time with hoist assisted beds.

People with MS and other neurological conditions, with high levels of complex needs, find it extremely challenging to source appropriate respite. **In 2022, 75% of those availing of services were in the high dependency category.** Due to the progressive nature of MS, MS Ireland's respite centre is best placed to provide the care needed for a complex and unpredictable condition.

The respite service plays a vital role in offering people connections to other available services in the community and promoting mental health. Peer compatibility of respite users is considered at the time of reserving respite beds. The respite service is confident that it is successful in achieving the **peer support** element because of the consistent re-booking of users and requests by groups to attend together. The availability of transport and a driver is an extremely important aspect of any respite service in ensuring that respite users can get out into the community, with this in mind the respite service has its own wheelchair accessible minibus.



MS Ireland's respite service is **specialist** in its knowledge and management of symptoms of MS and other neurological conditions and offers a high quality, person centred service to those availing of respite there. Referrals are accepted from all over the country, proving that our service is **accessible and equitable**.

Service users enjoy activities of their choosing during their stay such as yoga, massage, hairdressing, chiropody, social outings etc. There is an emphasis on education and self-management strategies. Service users can avail of physiotherapy assessments and/or an appointment with the nurse specialist during their stay. Following the assessments, further referrals back to the relevant Primary Care and Disability teams may be made on behalf of the client to ensure continuity of care following their respite stay.

The respite centre requests service users feedback their experience of the care provided to ensure that we are meeting the needs of the service user and their carers. This information informs MS Ireland's delivery of care. **In 2022 service users reported 100% satisfaction in the care provided by Nursing and Care staff, in the support received by the MS support nurse and with the physiotherapy service they received during their stay.**

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Respite Centre Income and Expenditure

	Actual 2022	Budget 2023	Budget 2024
Available bed nights	1997	3696	4200
	€	€	€
HSE Funding	928,284	951,215	951,215
Private Health Insurance	161,384	200,701	228,069
Medical Cards	9,090	11,435	12,994
Voluntary contribution	31,300		
Rental income	57,121	57,121	57,121
Total Income	1,187,179	1,220,472	1,249,400
Salary	828,499	1,085,986	1,194,585
Other Operating Costs	502,639	545,503	681,879
Total Costs	1,331,138	1,631,489	1,876,463
Additional Funds being sought from HSE	(143,959)	(411,017)	(627,064)

Notes:

- HSE funding is stated at current levels under existing Service Level Agreements. This is used exclusively for the payment of wages and salaries.
- Private health insurance income and medical card income increases predicted in line with the increase in available bed nights.
- Voluntary contributions are unpredictable and ignored on prudence grounds.
- Increased headcount to service additional bed nights will result in a 10% year on year increase in payroll costs.
- Other operating cost increases in line with the increase in available bed nights.
- To date, deficits have been funded from the reserves of MS Ireland. In the current economic climate and with fundraising income declining, there is no certainty that MS Ireland will have the capacity to do this.
- Full cost effectiveness, and therefore value for money, is best achieved by operating at full capacity.
 - » As the Respite Centre reaches capacity, the average employee cost and total cost per bed night decreases.
 - » There will also be a decrease in the HSE funding per bed night in 2024 compared to 2022.

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The Costs and the Consequences

MS Ireland’s respite service experiences an annual deficit and the shortfall is sourced by MS Ireland’s National Fundraising team. Unfortunately, due to the current cost of living crisis and living in a post-covid world, fundraising is becoming increasingly challenging.

To respond to funding cuts imposed in 2008 (€257,432) and a growing deficit, MS Ireland closes its 12-bed respite centre every second weekend and the days following a bank holiday. The necessity to restrict the operational hours of the respite service to reduce costs, limits the cost efficiency of the service. An additional €627,000 will increase the respite service availability to people with MS and other neurological conditions.

MS Ireland is committed to the continued delivery of high-quality respite. However, due to increasing levels of dependency, higher costs associated with complying with HIQA standards and increasing fundraising challenges, MS Ireland requires additional funding to continue to operate. Increased funding means returning to full opening i.e., open every weekend and the days following

a bank holiday, putting an additional 1,248 bed nights back into the system.

MS Ireland recognises the capacity issues facing the HSE regarding respite provision and our proposal will assist with alleviating respite waiting lists. In addition, due to the person-centred and specialist nature of the respite service i.e., neurological physio assessments and nursing assessments, it ensures that needs are being identified which can avoid or assist with health or social issues later, therefore lowering the level of intervention required by disability and primary care teams.

89% of respondents staying at the National MS Respite Centre indicated the respite care had met their needs.

My MS My Needs Survey 2023

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Our Proposal

In Ireland today there is an over reliance on acute hospitals to provide care, we must move towards an integrated health system with strengthened primary, community and long-stay structures.

Residential care is experiencing pressure in providing age and need-appropriate respite services. Home support services are also experiencing pressure in providing home support and in-home respite. As a result, increased centre-based respite is required more than ever.

In order to alleviate the pressure already identified on respite services, MS Ireland is seeking an additional €627,000 to increase respite availability to people with Multiple Sclerosis and other neurological conditions. This additional funding will increase bed availability by 12 weeks and provide an additional 1,248 respite bed nights per year.

Benefits of this proposal include:

- Increases respite availability for people with MS and other neurological conditions, which is age and need appropriate.
- Reduces pressure on carers across the country and prevents breakdown of informal care arrangements.
- Provides opportunities for peer support in an appropriate community setting.
- Avoids crises by providing planned respite as an early intervention
- Assists respite users and their carers to safeguard their physical, emotional and mental health.
- Relieves pressure points on an already inadequate number of respite beds nationally.

- Delivery of increased respite by an experienced service provider, with strong clinical and organisational governance consisting of an experienced clinical team with in-depth, specialist knowledge of neurological conditions
- Increases opportunities for education, self-management strategies and peer learning.
- Opportunity for referral within the suite of MS Ireland services and to disability/primary care teams, reducing secondary complications, in keeping with *right place, right time, right expertise*.



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Conclusion

MS Ireland is seeking an additional €627,000 to increase respite availability to people with Multiple Sclerosis and other neurological conditions. An additional €627,000 will increase bed availability by 12 weeks, providing an additional 1,248 respite bed nights per year. In 2022, the respite centre welcomed people with MS, Parkinson's, Ataxia, Stroke, Spinal Injuries, ME and Muscular Dystrophy.

The benefits of this proposal are multiple, the obvious and most important benefits being the positive experience for the service user and respite for the carer. With additional funding, MS Ireland would continue to play a vital role in providing services and increasing respite availability.

There are growing capacity challenges facing the HSE with increasing demands on residential beds, home support hours and respite services. MS Ireland could alleviate some of the pressure points on services with additional funding. The HSE Capacity Review, Slaintecare Report and Neurorehabilitation Strategy's underlying principle is that services

must be integrated, proactive, community-based with an emphasis on planned models of care. MS Ireland's Respite Service along with a suite of other services delivers this model of care.





Kate is 89 years old and has been a carer for the best part of her life.

Kate's Story

Kate and Tom were married for 52 years and had three children. Shortly after they were married, Tom was diagnosed with MS. Tom worked until the age of 56 but retired due to his MS. Tom attended MS Ireland's respite centre for scheduled respite for both him and his wife Kate. Kate was Tom's Primary Carer until he passed away at the age of 82 years.

Kate and Tom's daughter Sarah was diagnosed with MS at the age of 25 and

has lived with MS for the last 30 years. Kate is Sarah's Primary Carer. Sarah, now 55, attends MS Ireland's respite service. Kate and her other family have advised that without the support of MS Ireland's respite service, nursing home care would have been the only option available to them. Sarah's siblings support with her care as much as they can but it impacts their family lives. Kate is 89 years old and has been a carer for the best part of her life.





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