



# Care Centre Business Case

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The Multiple Sclerosis Society of Ireland

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 Care Centre Business Case

## Executive Summary

The Multiple Sclerosis (MS) Care Centre is a 12 bedded unit which provides respite care for people with MS (PwMS) and other progressive neurological conditions. At present, the Care Centre is only open for 40 weeks per year as a result of decreases in both Statutory and fundraised income over the last number of years. We want to return to a situation where we are open 50 weeks of the year to meet increased demand.

The cost of MS to Society is estimated at €429 million per annum, €129 million of which relates to direct costs such as hospitals, doctors and medication (€14,300 per PwMS per annum), and €77.8 million to the provision of informal care for people with MS.\* Interventions that reduce relapses and disability progression, support working and living independently, can reduce these costs by as much as €29 million per annum.

Our Care centre provides a modern state-of-the-art respite service, which focuses not just on providing a break for the PwMS & their caregivers, but delivers a range of therapeutic services, neurological assessments and many social activities, all designed to revitalise and rejuvenate and prevent crisis. Respite services are also a key enabler to ensuring the continuation of the voluntary support provided by family members.

The MS Care Centre employs 30 people from a wide variety of backgrounds. We also provide 26 opportunities, through the Community Employment (CE) Scheme, for people looking to get back to work each year, providing excellent training opportunities in care, maintenance, administration etc.

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 care structures. MS Ireland currently provides respite at a relatively low cost in a community setting (from €423 to €615 per night in comparison to approximately €2,000 at major teaching hospitals).

**To restore the Care Centre to operating 350 days in 2019, providing an additional 1,128 bed nights per year, we require an increase in funding of only €600,000 per annum (see Table 2 of page 9). A very small investment when one considers the impact our respite centre can have on the lives of PwMS and their caregivers, as well as the overall reduction of the costs of MS to society.**

## Introduction to Multiple Sclerosis

MS is described as a chronic condition of the Central Nervous System (CNS). The CNS consists of the brain and spinal cord. The symptoms experienced with MS are caused by patchworks of demyelination or scarring, in the CNS. It is not yet known what triggers the process of scarring. MS can occur at any stage of the life course for people from their mid to late teens and into old age. As the disease progresses the degree of disability increases markedly from low dependency needs to requiring very high levels of care.

Multiple Sclerosis (MS) is reported as the most common disabling neurological condition of young adults. Prevalence studies would suggest that MS currently affects over 9,000 people in Ireland. Information from the Central Statistics Office (CSO) indicates that some 43% of our population is under the age of 30. As most diagnoses of MS occur at this age it is likely that the number of cases of MS will rise significantly in the immediate future as this cohort ages. Currently, nine out of ten people with MS are of working age.

\*Societal Cost of Multiple Sclerosis in Ireland 2015

## The MS Care Centre

The MS Care Centre comprises of 12 ensuite accessible bedrooms. There are two sitting rooms, a quiet room, dining room, coffee dock, physiotherapy suite, library/art room, boardroom, reception area offices and three public wheelchair accessible toilets. The complement of staff is such that the Care Centre can meet the needs of residents in the low to high care dependency level category. The Care Centre can accommodate a maximum of six high care dependency residents at any one time with hoist assisted beds. It is our experience that people with high levels of complex needs find it impossible to source appropriate respite. The facilities of the MS Care Centre, both in terms of the equipment and the skills and experience of our dedicated staff, provide a unique environment to meet these needs in a community setting.

Many family members that provide care for people with MS are familiar with the Care Centre and engage with us each year to provide short term respite care for their loved one. Each week a maximum of 12 residents can enjoy a number of social and therapeutic activities such as yoga, massage, day trips, physiotherapy, and a personalised neurological nursing assessment. The Care Centre caters for approximately 400 admissions annually. At present, admissions can be for 5, 7 or 12 nights depending on individual circumstances and requests. See Appendix 2 for a breakdown of admissions by region and neurological conditions.

Referrals or enquiries for admission may come from acute hospitals, discharge coordinators, community based professionals or directly from persons affected by MS. Pre-assessment will be completed to ensure that all necessary equipment, knowledge and competency are available to meet the resident's needs. The following is the category of care levels we provide respite for:

- » **A2** assistance of two staff with all care needs including assistance with meals
- » **A1** assistance of two care staff with all care needs excluding assistance with meals
- » **B** assistance of one staff with all care needs
- » **C** Independent

**"I was diagnosed with Multiple Sclerosis in 1983 and have been coming to the MS Care Centre on a regular basis over the last 20 years. When I first came to the centre I walked in with the aid of a stick, however now I use an electric wheel chair and I need a high level of care. As my MS progressed and my level of care increased, the centre continued to offer me a service. The Care Centre is my lifeline and the only place that can meet my needs."**

*Deirdre, PwMS*

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Care Centre Business Case

The MS Care Centre is Health Information Quality Authority (HIQA) registered and offers short-term respite care mainly to people with MS. We also extend our services to those with other neurological conditions. Our 'home away from home' is a place of rest and relaxation for people with MS from all over Ireland. Residents receive therapeutic services, neurological assessments and many social activities in a homely environment in the suburbs of Dublin. As the MS Care Centre is the only dedicated respite centre for people with MS in Ireland it is a place for residents to learn more about their MS and find ways to self-manage their condition.

**Within the MS Care Centre the aim of respite is to:**

- » Provide the support needed to help individuals remain at home, sustain caring relationships, prevent crises, and live the life of their choice to their fullest potential
- » Support both PwMS & carers to continue to work
- » Help both clients and carers to safeguard their health, avoiding physical or emotional exhaustion and enable them to continue caring and living a life of their choice
- » Provide regular and flexible breaks as an early intervention which helps in preventing crises

**All staff at the MS Care Centre (Appendix 1) are committed to:**

- » Developing and improving the quality of life of residents
- » Preserving the autonomy of residents and promoting free expression of opinion and freedom of choice
- » Maintaining a safe physical and emotional environment

- » Ensuring the privacy, respect and the dignity of residents
- » Supporting and respecting the rights of all persons employed in the service and providing continuing ongoing professional development
- » Providing formal training to staff to equip them with the skills and competencies necessary to meet the needs of residents.

**Community Employment Scheme**

The Community Employment Scheme (CE) at the Care Centre is a vital part of the work carried out there. Given the high levels of care that our residents require, these participants are now an essential addition to the team primarily involved in direct care. Participants are also involved in administrative support and maintenance.

All of these functions are essential to the provision of the high standard of care that is provided at the centre. The scheme has approval for 26 participants at present. The annual contribution from the Department of Social Protection in relation to the scheme is €328,000 per year approx. The numbers of CE participants that subsequently gain fulltime employment in the provision of care services in 2017 was 60% and 7% to education.

**"I joined the CE scheme in May 2015. During my time on Community Employment I gained valuable experience and training and also completed my QQI Level 5 Healthcare Support Award. On completion of my time on the project I felt I was equipped with the necessary skills to enter the work force. I am now a full time Care Assistant with St Raphael's Day Services in Maynooth Co Kildare"**

*Josephine Ndebele*

## Caring for people with MS

Caregivers of people with MS spend an increasing number of hours each week providing care. Of these caregivers, 64% are emotionally drained, 32% experience depression and 22% have lost a job due to caregiving responsibilities.

Recent estimates suggest total annual societal costs attributable to the provision of informal care for people with MS are €77.8 million<sup>1</sup>. **Respite services are a key enabler to ensuring the continuation of the voluntary support provided by family members.** We know 63% received an average of 15 hours of care from family members or friends in the previous week (Societal Costs) & 73% of people with MS receive care and support from a family member or friend (from My MS My Needs).

**“It’s so important for PwMS to have a respite centre to go to, not just for ourselves, but for the people looking after us – I would be heartbroken without it, which speaks for it really”**

*Laura PwMS, Kerry*

The MS Care Centre delivers quality respite care that supports the person with MS by providing assessment to help them manage their condition. The Care Centre also provides therapeutic services that help those staying with us to build up their emotional and physical strength. The Care Centre

supports the wellbeing of family caregivers which facilitates the continued care of the person with MS in their own home. In recent times the greatest demand for respite is from people with MS who fall into the high dependency range. In 2017 almost 80% of those availing of the services provided by our Care Centre were in the high dependency category.

**“We as a family could not continue to care for Ciaran at home without the constant knowledge that we will be able to access respite care for him in such a safe environment as the MS Care Centre and to this standard.”**

*Janet Lambe, wife of Ciaran,  
Diagnosed in 1996*

**“If they ever tried to close it down I would go out and demonstrate, the government would have to step up to the mark and realise what its like for people like us in a wheelchair and how important a facility like the Care Centre is.”**

*Edel PwMS, Roscommon*

<sup>1</sup>MS Ireland, 2015. Societal Costs of Multiple Sclerosis in Ireland. Dublin: MS Ireland and Novartis

## The Finances of the Care Centre

Table 1 below outlines the cost per bed night depending on the length of stay and the residents' level of dependency:

**"I go there to meet up with other people, I don't get out very much and gives my wife a break, its great for rest- I enjoy the activities and the music they have at night."**

*Jack PwMS, Galway*

Table 1

	A2			A1			B			C		
	5 Nights	7 Nights	12 Nights	5 Nights	7 Nights	12 Nights	5 Nights	7 Nights	12 Nights	5 Nights	7 Nights	12 Nights
<b>Total Cost</b>	€3,076	€4,272	€7,263	€2,615	€3,628	€6,158	€2,203	€3,049	€5,166	€2,167	€3,000	€5,083

Table 1 shows how the cost of care increases in line with the progression of the disease with the cost of an A2 resident some €1,200 higher per week than the cost of respite provided to a person with the lowest level of disability. The Table also shows that a stay of 5 nights is less than €500 per night for category C residents and approximately €600 for an A2 resident.

representatives. The 10% cut was matched by a 10% reduction in hours worked by staff and the impact on the Care Centre was to close every second weekend and for the days after the bank holiday. We took these actions in order to seek to maintain some level of services, but manage within our budget.

The annual HSE funding is €257,432 lower now than it was in 2008. Income from client contributions was also reduced by €99,634. Annual Care Centre deficits relied on funding from MS Ireland's national fundraising team but unfortunately funding from this source has proved very challenging as the recession took hold and continuing with the publicity surrounding recent scandals in the Charity sector. Revenues from national fundraising have declined from €1,356,427 in 2008 to €711,053 projected for 2018, a 47% decrease.

**"I know from the moment I go inside that door, I am cared for instantly, my worries go away from the moment I go in that door, they take my bags, make sure I am ok, provide me with food and tea, it's a safe place to go, you feel happy knowing that everyone there is looking after you"**

*Edel PwMS, Roscommon*

MS Ireland suspended staff increments and in 2012 we instituted a 10% reduction in hours. A number of redundancies were also agreed with the staff and their union

## The Business Case

As far back as 2008 the HSE indicated that the daily operating cost of an inpatient bed in a major teaching hospital is approximately €2K (PA Consulting Acute Hospital Bed Capacity Review 2008). The report concluded that there is an over-reliance on acute hospitals to provide care and that there should be more reliance on an integrated health system with strengthened primary, community and long-stay care structures, and a change in acute hospital practice to allow for the more efficient usage of available beds. The review admitted, however, that at present, the Hospital service is over 1,100 acute beds short of the number needed to cope with the current pressures on the system. It said that if current practices and processes continue and if there is not appropriate investment in community facilities, the demand for hospital beds could reach 20,000 by 2020 - currently we have around 12,000 acute hospital beds.

MS Ireland currently provides respite at relatively low cost in a community setting. This service can be easily expanded by reopening the Care Centre the weekends/days that it is closed.

MS Ireland is committed to the continued delivery of high quality respite but we are cognisant of the challenging environment. This environment includes the increasing levels of dependency and complexity of our cohort together with increasing challenges within the fundraising space and higher costs associated with legislative requirements to comply with HIQA standards. In order to meet these challenges MS Ireland requires additional funding to continue to operate.

## Our Proposal

MS Ireland is continuing to make every effort to reduce the operational deficit at the Care Centre. However, the necessity to restrict the operational hours of the Care Centre in order to reduce costs limits the cost efficiency of the Care Centre. A return to 'full' service on a cost recovery basis will improve the cost effectiveness of the service which can be offered and thus better service the needs of PwMS and help to protect the future viability of the Care Centre.

We want to return to a situation where we are open 50 weeks of the year to meet the increased demand for our services. This means that we would be operational every weekend and all bank holiday weekends as currently this is not the case due to the cost containment measures taken by MS Ireland in 2012. These measures limit the availability of respite to breaks of 5, 7 or 12 nights which also means that this is not the most effective use of the service due to the nature of fixed costs.

**MS Ireland is seeking full cost recovery to enable us to open 50 weeks a year to meet the demand for this specialist type respite for people with progressive neurological conditions. To restore the Care Centre to operating 350 days in 2019, providing an additional 1,128 bed nights per year, we require additional funding of €515,984 per annum (see Table 2 page 9).**

**"You connect and communicate with other PwMS, it's the social side really, people there become your friends. The yoga, the physio and the MS nurse we get to meet them. The nurse is the most important and very valuable the support she offers, it's the only time I get to see the MS nurse and I can talk to her about anything."**

*Laura PwMS, Kerry*

Care Centre Business Case

Table 2: Care Centre Income & Expenditure (including MS Ireland Fundraised income)

	Actual 2017	Projected 2018	Projected 2019	Projected 2020
<b>Available Bed Nights</b>	<b>3,072</b>	<b>3,108</b>	<b>4,236</b>	<b>4,236</b>
HSE Funding	851,523	863,952	863,952	863,952
<b>Client Contribution</b>				
Private Health Insurance	204,442	204,442	198,309	192,360
Medical Cards	8,300	8,140	7,896	7,659
Voluntary Contribution	20,645	18,360	17,809	17,275
<b>CEP funding</b>	<b>328,715</b>	<b>328,715</b>	<b>328,715</b>	<b>328,715</b>
<b>Funded by Donations &amp; Fundraising</b>	<b>233,703</b>	<b>256,809</b>	<b>170,400</b>	<b>159,910</b>
<b>Total Income</b>	<b>1,647,328</b>	<b>1,680,418</b>	<b>1,587,081</b>	<b>1,569,871</b>
Salary	870,172	887,387	887,635	887,890
<b>Other operating costs</b>	<b>446,398</b>	<b>462,273</b>	<b>467,676</b>	<b>474,726</b>
<b>CEP costs</b>	<b>330,758</b>	<b>330,758</b>	<b>330,758</b>	<b>330,758</b>
<b>Restoration of full hours</b>			416,996	416,996
<b>Total Costs</b>	<b>1,647,328</b>	<b>1,680,418</b>	<b>2,103,065</b>	<b>2,110,370</b>
<b>Additional funds being sought from HSE</b>	<b>0</b>	<b>0</b>	<b>(515,984)</b>	<b>(540,499)</b>

In 2017 and 2018 the operating deficit was fully covered by MS Ireland fundraising income/reserves.

Additional arguments for the increase in funding from the HSE are as follows:

- » Over 9,000 people in Ireland are living with MS and the MS Care Centre is uniquely set up to provide respite to those that need it most.
- » MS Ireland has a proven track record in delivering specialised care for people with MS.
- » The Care Centre is registered by HIQA.
- » The needs of Care Centre residents are becoming more complex and costly due to the progressive nature of the illness and the Care Centre can cater for the most complex cases at c. €600 per bed night which is relatively inexpensive.
- » The Care Centre will continue to augment the financial support it receives from the HSE with funds raised from private sources.
- » Respite in the Care Centre helps to preserve the wellbeing of residents and thus reduces the societal costs of caring for them.
- » The Care Centre supports the home care of people living with MS and relieves the pressure on state services which otherwise would be much greater if this care had to be directly provided by the HSE.

**For additional information please do not hesitate to contact:**

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Financial Accountant

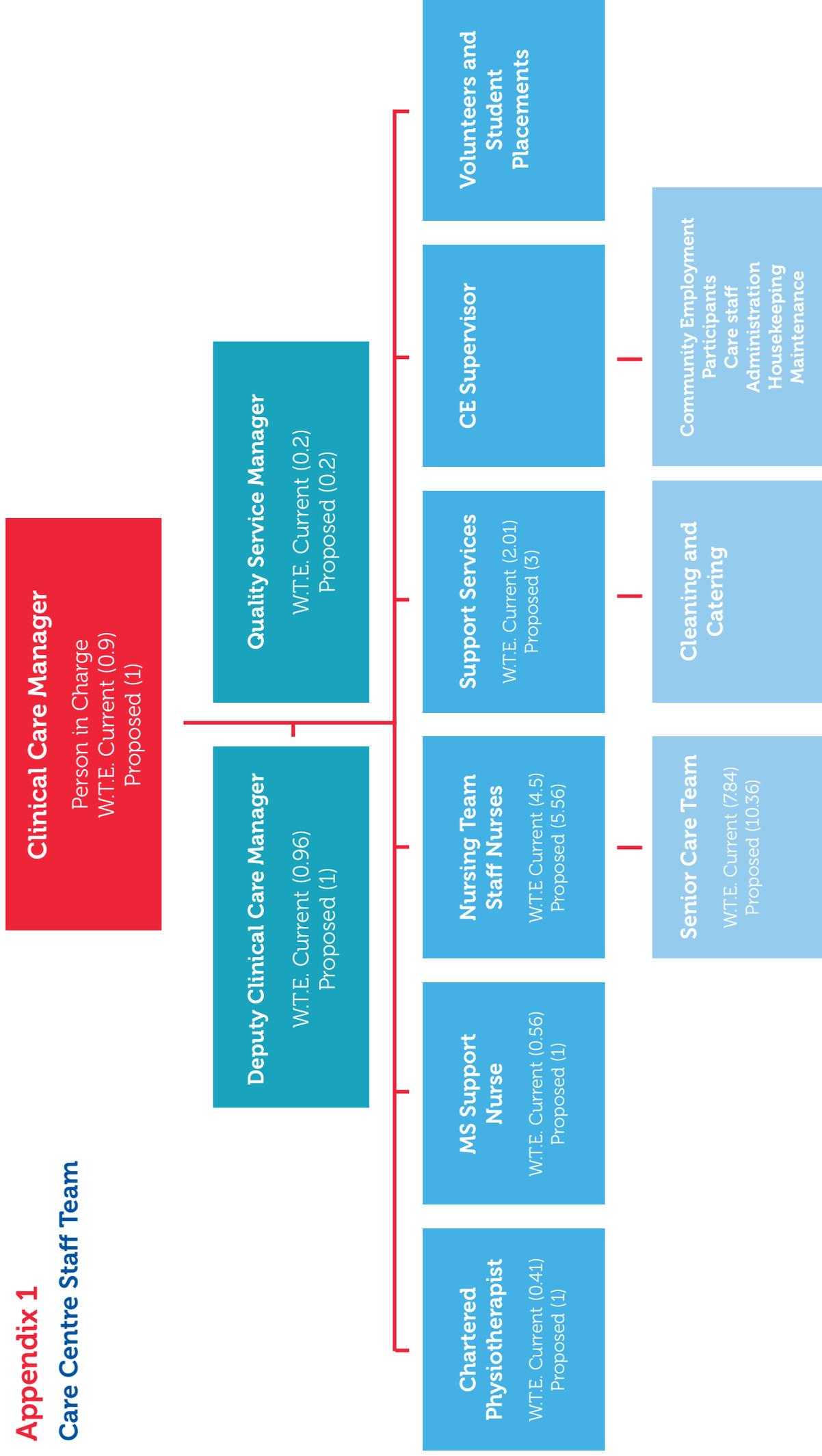
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## Appendix 1

### Care Centre Staff Team



## Appendix 2

### January - December 2017 Statistics for the MS Care Centre

	Residents	Bed Nights
Male	139	926
Female	268	1809
<b>Total</b>	<b>407</b>	<b>2735</b>
<b>Regions</b>		
South Western Area	103	684
East Coast Area	84	508
Northern Area	57	407
Mid West Area	23	145
North East Area	39	262
South East Area	19	130
Midlands Area	10	75
Southern Area	19	130
North Western Area	9	59
Western Area	43	328
Outside 26 counties	1	7
<b>Total</b>	<b>407</b>	<b>2735</b>
A3: Total dependency	4	24
A2: Total dependency	76	515
A1: Total dependency	107	743
B: High dependency	135	908
C: Moderate dependency	85	545
<b>Total</b>	<b>407</b>	<b>2735</b>
Multiple Sclerosis	344	2339
Other Neurological Conditions	63	396
<b>Total</b>	<b>407</b>	<b>2735</b>



## Multiple Sclerosis Ireland

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