

Towards Equality for People with Multiple Sclerosis



**Multiple Sclerosis Ireland
Pre-Budget Submission
2007**



Helpline: 1850 233 233
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An Introduction

Multiple Sclerosis is one of the most prevalent diseases of the central nervous system and directly affects an estimated 7,000 people in Ireland. It is the most common disabling neurological disorder amongst young people but it can occur at any age.

The long-term disabling symptoms of MS result in a high socio-economic cost to individuals, families, employers and society as a whole.

People with Multiple Sclerosis and their families require our society to enable them to access:

- Services that provide effective diagnosis and treatment to manage symptoms
- Services that support quality of life

In his budget statement delivered to the Dail on 7 December 2005, Mr Brian Cowan, TD, Minister for Finance said:

"We are living in the midst of the longest and strongest era of sustained prosperity in all of Irish history.....As a nation, we now enjoy a much enhanced quality of life. We are a prosperous country. More of our citizens are in work than at any time in our history. More enjoy a decent quality of life than ever before."

Despite these optimistic words, there has been little significant improvement in the lives of people with Multiple Sclerosis and although it is generally accepted that in overall terms the Irish economic background remains favourable, the benefits of the "Celtic Tiger" has had little impact on their lives.

It is predicted that the GDP growth at the end of this fiscal year will be around 4.5%, yet there is increasing evidence that people with disabilities are discriminated against; it is difficult for them to gain access to services and these difficulties are exacerbated by their economic circumstances.

The existing gaps in health care services are well recognised and are the focus for all voluntary bodies currently advocating for and providing services to the disabled, their carers and families. The Government has made many commitments and promises to address gaps in the Programme for Government 'Towards 2016'. However promises only make a difference when they result in delivery.

Amongst the many issues requiring additional funding such as home help, personal assistants, accessible transport and suitable respite care, there are seven areas of major concern which Multiple Sclerosis Ireland wish to see addressed.

Multiple Sclerosis Ireland Calls on the Government to:

Invest in services and supports for people with Multiple Sclerosis and their families and carers by providing additional resources to address the lack of adequate, timely services for people with Multiple Sclerosis. Progress must be made to deliver critical and essential services.

Specifically MS Ireland is seeking

1. An increase in the number of Neurologists and associated multi-disciplinary teams to be brought to the recommended EU level of 39, within a 3 year timeframe, commencing in 2007
2. The provision of the required staff and facilities for the delivery of Tysabri and other newly approved treatments on an equitable basis throughout the country
3. The introduction of a Cost of Disability payment of €40 per week for all people with MS
4. A significant increase in the Disabled Persons Housing Grant and to ensure equity of access throughout the country
5. The issuing of a medical card to every person diagnosed with MS
6. The assurance that the necessary physiotherapy services are made available to people with MS on an equitable basis throughout the country
7. A review of the current criteria for drivers tax concessions, so that anyone diagnosed with Multiple Sclerosis automatically becomes eligible for these rebates.

Details of Submissions

Item 1: Lack of Neurological Services

Access to neurological services is an on-going problem for people with Multiple Sclerosis and it is imperative that provision be made in the budget to address these issues. It is now universally established and recommended that early and aggressive treatment is the best course of action to alleviate symptoms in those newly diagnosed. It is therefore vital for people to have an early consultation with a Neurologist.

The huge gaps in the provision of neurological services in Ireland were identified by the Neurological Alliance of Ireland in three Standards of Care Documents, published between 1999 and 2002. A series of far-reaching recommendations was generated. Hospital-based neurological services were reviewed in detail by Comhairle na nOspideal between 2001-2003. Despite these reviews, there has been no significant increase in the number of Neurologists in Ireland, which still has the lowest ratio of Neurologists per capita in Europe.¹

It must also be recognised that some patients on existing Neurological lists have waited for up to two years to be seen and that many patients with Neurological conditions are never reviewed by a Neurologist.

The EU recommend that Ireland should have 39 Neurologists and associated multi-disciplinary teams, geographically centered to meet demands by people with Multiple Sclerosis. Taking into account the 4 or 5 approved positions still not filled, there are currently only 17 Neurologists in place, with regional gaps. For example, despite experiencing the highest incidence of Multiple Sclerosis in the country, the North West still has no Neurologist with people having to travel to Dublin or Galway.

MS Ireland calls on the Government to bring the number of neurologists associated multi-disciplinary teams to the minimum recommended EU level of 39 within a three year time frame commencing in 2007

¹ Neurological Alliance of Ireland: Services for Neurological Conditions in Ireland: The Standards of Care (S.O.C) documents

Details of Submissions

Item 2: Provision of Tysabri and other suitable newly approved treatments for people with MS

On June 29, 2006, Elan and Biogen Idec announced that they received approval from the European Commission to market TYSABRI as a treatment for relapsing remitting multiple sclerosis and to delay the progression of disability and reduce the frequency of relapses.²

As there is yet no cure for MS, any drug that relieves symptoms and/or slows down progression is welcome by the thousands of people living with MS. This news was warmly welcomed by MS Ireland; the introduction of Tysabri and other newly approved treatments, offers significant hope to those people living with relapsing-remitting MS in Ireland.

Evidence shows that Tysabri reduces the number of relapses and slows down the progression of MS. Delivery of the drug is by intravenous injection once every four weeks and this will require several hours in-patient treatment either in hospital or at a medical centre. However, the current crisis in the health service does not bode well for the delivery of this treatment and it is likely that access to this treatment will be hampered by lack of funds, lack of trained staff and shortage of suitable facilities.

MS Ireland calls on the Government to provide the required staff and facilities for the delivery of Tysabri and other approved treatments on a equitably basis throughout the country

Item 3: Cost of Disability Payment

It is recognised that the daily cost of living for people with a disability is higher than for the general public and many disabled people experience a lower standard of living because of their disability. Amongst the many items adding increased costs are transport needs, housing adaptations, disability aids and appliances, heating, care assistants and home help. In 2005 a report by the Department of Community & Social Affairs showed that 66.5% of people with a disability fall below the 60% level of median income, and 22.5% suffer basic deprivation.³

A European Union study in 1996 indicated that 42% of households headed by a person with a disability were living below the poverty line.⁴

Current research indicates that people with a disability are far less likely to be in paid work and a diagnosis of MS often means the end of paid employment. Indeed, recent research conducted by MS Ireland indicates that 73% of people with MS are unemployed. Multiple Sclerosis Ireland is calling for the introduction of a cost of disability payment to cover these extra costs.⁵

MS Ireland calls on the Government to introduce a Cost of Disability payment of €40 per week for all people with Multiple Sclerosis

² Biogen Idec : Press Release July 2006

³ NDA: Disability and the Cost of Living

⁴ Irish Wheelchair Association: Resources, Deprivation and the Measurement of Poverty",

⁵ Combat Poverty : Poverty In Ireland - data from EU-SILC 2004

Details of Submissions

Item 4: Disabled Persons Housing Grant

The Disabled Persons Housing Grant provides essential financial support to people who have to adapt their home to enable them to create or improve mobility. This scheme is invaluable, however many local authorities have long waiting lists and some areas have introduced arbitrary means testing procedures. Many councils do not have adequate budgets and are unable to meet any of the costs involved, let alone the suggested 90%.⁶

The housing needs of people with disabilities have never been properly addressed and many people with Multiple Sclerosis are currently living in appalling conditions, lacking proper toilet and bathing facilities and in many cases living in one room as the rest of the house is inaccessible. MS Ireland welcomes the Dept. Environment's sectoral plan objective to encourage and facilitate access to appropriate housing and accommodation for people with disabilities. However, people cannot wait years to be able to move around their home. Action is needed now.

One method of meeting these needs would be to remove the financial onus from local councils, with the entire cost being met by central funds.

MS Ireland calls on the Government to make a significant increase in the Disabled Persons Housing grant and to ensure equity of access throughout the country.

Item 5: Medical Cards

Income guidelines for medical card holders have not kept pace with social welfare increases. The medical costs associated with Multiple Sclerosis as a progressive disabling disease is high. Regular medical attention is needed at both GP and consultative level, as is occasional and on going drug treatments, plus physiotherapy and other treatments. These are too costly to be sustained by people on an on-going basis.

MS Ireland calls on the Government to issue full medical cards to every person diagnosed with MS, irrespective of income.

Details of Submissions

Item 6: Lack of Access to Physiotherapists

The lives of many people with Multiple Sclerosis are hampered by the lack of access to Physiotherapists. Physiotherapy has a vital role to play in minimising the effects of MS as well as slowing its progression.

Research now finds that timely physiotherapy intervention, if appropriate, during a relapse phase speeds recovery and is critical in maintaining mobility, and enabling recovery to maximum function.

Physiotherapy is crucial on an ongoing basis to prevent muscle wastage and assists with maintaining daily living functions.

MS Ireland calls on the Government to ensure access to physiotherapy services for people with MS on an equitable basis throughout the country.

Item 7: Automatic qualification for drivers tax concessions

At present, drivers or passengers with physical disabilities (in receipt of a Primary Medical Certificate from the Health Service Executive) are entitled to claim exemption from Vehicle Registration Tax and Value Added Tax on their vehicles, as well as repayment of duty on fuel and exemption from annual road tax. These benefits are only available to those drivers or passengers who meet stringent conditions. This approach prevents many people with MS from benefiting from these rebates.

MS Ireland recognizes that access to motorized transport is essential to enable people to lead independent lives and participate in the community. The private car remains the most suitable option for many people, particularly those living in rural areas.

MS Ireland calls on the Government to review the current criteria for drivers tax concessions, in order that anyone diagnosed with MS automatically becomes eligible for these rebates.

An Introduction to MS Ireland

Mission Statement

The aim of the Society is to enable and empower people with MS to live the life of their choice to their fullest potential, to improve the quality of life for those principally affected and to help find a cure for Multiple Sclerosis.

Objectives

- To provide support for the families and carers of PWMS
- To co-operate with the medical, scientific, social and caring professions to promote scientific research into the causes of, cure for and management of MS, and the alleviation of medical and social symptoms
- Exchange and disseminate information relating to MS
- To provide an identifiable focal point by developing an efficient, effective and caring organisation to serve the needs of PWMS.

Services

The Society provides a wide range of services and programmes designed specifically to meet the needs of the MS community and to ensure that the fundamental objectives of the Society are achieved. Key Services:

- Confidential helpline, *1850 233 233*
- Respite Care Centre
- Professionally staffed Regional Offices
- Voluntary Branches, nationwide
- Professional counselling
- Advocacy and lobbying
- Booklets and Information Sheets
- *MSnews* magazine and e-newsletter
- Website www.ms-society.ie
- Funding for research projects
- National Conferences

National Office

80 Northumberland Road, Dublin 4
Tel: 01 678 1600 Fax: 01 678 1601
Helpline: 1850 233 233
Email: info@ms-society.ie
Web: www.ms-society.ie

MS Shop

56 Main St., Bray
Tel: 01 286 1913

MS Care Centre

65 Bushy Park Road, Rathgar, Dublin 6
Tel: 01 4906234 Fax: 01 490 6724
Email: mscare@ms-society.ie

Regions

Eastern Region, East Coast Area

Unit 10a, The Egan Centre, Dargle Road,
Bray, Co. Wicklow
Tel: 01 2866800 Fax: 01 272 4110
Email: eca@ms-society.ie

Eastern Region, South Western Area

65 Bushy Park Rd, Rathgar, Dublin 6
Tel: 01 256 9585 Fax: 490 6724
Email: swa@ms-society.ie

Eastern Region, Northern Area

65 Bushy Park Rd, Rathgar, Dublin 6
Tel: 01 256 9585 Fax: 490 6724
Email: na@ms-society.ie

South Eastern Region

Nuncio Road, Off Waterford Rd, Kilkenny
Tel: 056 77 51522 Fax: 056 77 71011
Email: southeast@ms-society.ie

Southern Region - Cork

North Quay House, Pope's Quay, Cork
Tel: 021 4300001 Fax: 021 4300533
Email: southern@ms-society.ie

Southern Region – Kerry

St. Mary's Parish Hall, St. Anne's Road,
Killarney. Co. Kerry
Tel: 064 30851 Fax: 064 30861
Email: siobhanl@ms-society.ie

Midlands Region

Newtown Terrace, Athlone, Co Westmeath
Tel: 090 6476353 Fax: 090 64 77466
Email: midlands@ms-society.ie

Mid Western Region

Old AIB Building, Castletroy, Limerick
Tel: 061 335565 Fax: 061 335565
Email: midwest@ms-society.ie

North Eastern Region

1 Church Street, Carrickmacross,
Co. Monaghan
Tel: 042 9664410 Fax: 042 969 2812
Email: northeast@ms-society.ie

Western Region

Roxboro House, Raleigh Road, Galway
Tel: 091 862478 Fax: 091 862511
Email: western@ms-society.ie

North Western Region

Unit 6 Rossvie Business Park, Port Road
Letterkenny, Co. Donegal
Tel: 074 9125017 Fax: 074 9123044
Email: northwest@ms-society.ie

Branch Network

Athlone	Kilkenny
Ballina	Laois
Ballinasloe	Leitrim
Bandon/Kinsale	Limerick
Bray	Limerick West
Carlow	Louth
Cavan	Longford
Clare	Mayo South
Cork City	Meath
Cork North West	Monaghan
Donegal	Mullingar
Dublin North	Offaly
Dublin South	Roscommon
Dublin West	Skib/Bantry
Dungarvan/Sth Tipp	Sligo
Fermoy	Tipperary
Galway	Tralee
Kerry North	Tuam
Kerry South	Waterford
Kildare	Wexford North
	Wexford South



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