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Foreword

Foreword by Ava Battles CEO MS Ireland & Chair of the Neurological Alliance of Ireland (NAI)

Friends

MS Ireland believes that People with Multiple Sclerosis (PwMS) should get the right treatment at the right time. This may seem like a very basic demand, and one that it would be hard to refuse, but the truth is that this is not the situation for many people in Ireland today.

Many PwMS and their families across the country will already be aware of the wide range of services MS Ireland provides on areas such as information, case management, education and direct care. Our new Campaign Handbook represents an addition to these services. While it is a new departure for us, it clearly draws on our role as advocates and information brokers. However, this initiative has a specific focus on empowerment – enabling PwMS to become the most effective advocates they can be for access to the clinically indicated and approved medicines they require.

Drawing on the experience of those who have campaigned successfully to get access to medicines, we have created a resource which is designed to help those who wish to do so, to campaign in a structured and well-informed way on their own behalf or that of a family member. The Handbook provides “how to” guidance on who to contact and what type of letter is likely to be effective. It proposes a measured, escalating approach in an easy to follow layout.

MS Ireland recognizes the pressures funders and service managers remain under to deliver care within limited resources. Equally, we would emphasise the obligation on the health system to be both equitable and responsive to user needs. All care is a partnership. This Campaign Handbook is designed to harness the increasing requirement for responsiveness in support of equity of access to medicines for all PwMS.

We believe our Campaign Handbook is innovative, a first in Ireland. It would not have been possible to create it without support from many individuals in Ireland and abroad, particularly MS UK and the neurologist who reviewed the information. I thank them all. We will continue to look for new ways in which to support people with MS and their families. In the meantime, I look forward to seeing the positive results of their campaigning efforts in the near future.



A handwritten signature in black ink that reads "Ava Battles".

Introduction

The Multiple Sclerosis Society of Ireland (MS Ireland) strongly believes that People with Multiple Sclerosis (PwMS) should have access to all licensed medicines for their condition no matter where they live in Ireland. However, the fact is that at present not everyone with Multiple Sclerosis (MS) does get equal access to treatments across the country. Indeed there have been cases where people with MS have been denied access to clinically indicated treatments altogether. This includes treatments, which have been approved by the formal HSE approval processes and for which all people with MS should be eligible for based on clinical assessment, which is reflective of current legislation as set out in the Health Act, 1970.

This Handbook is designed to help you to understand what your treatment options and rights are as well as to give practical advice on how to engage with the health system to ensure that you have access to the medicines that are right for you. The principal focus of this Handbook is therefore on medicines that have an indication for treating MS.

This Handbook focuses on access to MS treatments in Ireland and is for you if:

You believe your Hospital is not making certain licensed MS treatments available to you for budgetary reasons

You have been told that you are suitable for a medicine that is licensed but not reimbursed at a national level

You have been told you are suitable for licensed and reimbursed MS treatments but you cannot get the treatment, for whatever reason

This guide has been inspired by people affected by MS who have campaigned for better access to MS medicines.

For further information on MS, please visit the MS Ireland website
www.ms-society.ie

The Access to Medicines Campaign Handbook was launched in August 2015

MS Ireland and Access to Medicines

MS Ireland provides a wide range of services in the community for PwMS and their families. The diagnosis of MS can give rise to physical, emotional, psychosocial and functional consequences. MS Ireland can play an important role in supporting, educating and advising PwMS and their families from diagnosis throughout their journey with MS. The role can be multifaceted and can include recognising, promoting and enhancing the person's ability to meet their own needs, solve their own problems and to assist in mobilising the necessary resources to introduce self-management and independence.

What does MS Ireland do?

1. MS Ireland website www.ms-society.ie

Our website is one of the main ways we communicate with our community. It is often the first port of call and it is easily navigated. You will find information about living with MS, free downloadable booklets and information sheets covering a broad range of MS topics, e.g. fatigue, exercise, research developments, available services, activities and events, our fundraising campaigns and the work we do. You will also find links to our email updates, social media channels and our MS & Me Community blog and you can sign up to receive eNews for regular updates.

2. MS Information Line 1850 233 233:

The Information Line provides confidential information and support to those living with MS, their families, health professionals, employers and others affected by or interested in MS. The aims of the service are to provide:

- Support to those newly diagnosed or experiencing difficulties with their MS who need an opportunity to talk and discuss their fears and anxieties. This support is also available to family members as often the person with MS may not have accepted the changes MS has brought or be ready to talk about it.
- Accurate and sensitive information regarding

questions or queries a person with MS may have about a certain area of MS e.g. managing the symptoms, welfare entitlements, referral to a service etc.

3. Solution Focused Casework/Case Management

MS Ireland offers a case work service to PwMS and their families especially people with a new diagnosis enabling them to navigate the complex services system. Case work supports the person with MS early in the disease course and throughout the transitional changes that MS, as a disease, presents. The Case Work Service is available to any person with MS and their family members in dealing with the many challenges that they face as a family unit. The case worker collaborates with the multidisciplinary team, primary and secondary groups, provides support and liaises with other statutory and voluntary organisations on behalf of the PwMS and their family as required. Information on your local contact is available at www.ms-society.ie

4. Symptom Management/Educational Programmes

With the onset of MS, people can face significant challenges to their health and wellbeing. Community based symptom management and educational programmes are planned to enable people with MS and their carers/families to promote healthy life choices and positive mental health in a supportive environment. These programmes are run collaboratively with HSE personnel augmenting the quality of Primary Care in supporting the management of MS in the most appropriate setting. Programmes are aimed at supporting people with MS to improve their coping strategies and providing information so that people can better manage their condition and take responsibility for their own health and wellbeing. MS Ireland also runs a broad range of tailor made exercise programmes throughout the country. These programmes include physiotherapy led classes.

MS Ireland and Access to Medicines

5. The MS Care Centre

This is the only dedicated respite service for PwMS in Ireland, and is based in Bushy Park Rd, Rathgar Dublin.

MS Ireland's approach is to develop services that provide a more personalised system of support.

The MS Care Centre is a twelve-bed facility and has a multidisciplinary team, which includes MS Nurse Specialists, Clinical Nurses, Physiotherapist and Care Staff. Services at the MS Care Centre include:

- Short term respite.
- Multidisciplinary Team Neurological Assessment.
- Referral to local services, e.g. PCC physiotherapy, occupational therapy etc.

6. Information Service

Information is part of every service we provide as we talk to service users, send written information to them or refer them to the MS Ireland website. Information is a key aspect of living with MS as it enables and empowers people and families to make decisions about how they live their life. Information assists people to choose medications, where to go for medical advice, who to contact in the community regarding interventions, how to manage symptoms, how to talk to their family about MS, where to go for support and to meet other people.

MS Ireland aims to provide the MS community with accurate, sensitive, timely and user-friendly information on a variety of topics related to MS. Topics are limitless but may include information on symptom management, exercise, accessing hospital or community services, entitlements, emotional coping strategies, caring, housing etc. MS Ireland's information tools include a variety of booklets and information sheets and the website

www.ms-society.ie

7. Research

Research is a key component in improving the health and quality of life for PwMS. Investigations to improve the understanding of the condition's mechanism, developing disease modifying therapies, translational research into how this knowledge can be useful and practical, what interventions can be beneficial, e.g. exercise, and how service delivery can positively impact, are all considerations driving the research agenda. This is most often stimulated by the scientific and social science community and the desire of people with MS to better understand, manage, prevent or in many cases cure their conditions. Aligned to these driving forces are the many commercial aspects of research and responsibility of the state to provide more efficacious and appropriate responses to population health. MS Ireland has a long history in funding and supporting research in many areas of MS and supports projects as funding becomes available.

8. Advocacy Role

To represent the views and concerns of PwMS at local, national and international levels. Advocating on an individual and collective platform for the improvement in services, resources and policies affecting PwMS.

MS Ireland also advocates on MS specific issues e.g. access to appropriate and suitable treatments for PwMS.

9. Local Voluntary Branches

MS Ireland has a network of 38 voluntary Branches nationally that are supported by MS Ireland nationally and regionally. Voluntary Branches are run for people affected by MS by people affected by MS. Anyone can become a member of a Branch and can decide how active or not they become. Some choose to become committee members and get involved in the running of the Branch, others may volunteer from time to time or just choose to receive services or attend activities.

About MS Medicines

MS Ireland believes that everyone should get the right treatment at the right time. Depending on the type of MS you have, the right treatment may not be a drug treatment but physical or supportive treatments. To help you get the right medicines at the right time, two things need to happen:

- You need information about the full range of treatment options available, so you can make an informed choice.
- You need to know how local systems and processes work, so you can get the medicines you are eligible for.

How can I get reliable and independent information about MS medicines?

If you are thinking about your treatment options, the resources below might be helpful. They are a useful starting point before you discuss things in depth with your neurologist or other healthcare professionals.

1. **Get Informed**

Read the guide on MS Ireland's website on Disease Modifying Treatments (DMTs) within the section Treating & Managing MS. This looks at all the DMTs for MS in more detail. (<http://www.ms-society.ie/pages/living-with-ms/treating-&-managing-ms/disease-modifying-therapies>). It is also important to understand that not everyone with MS is suitable for all the various drug treatments for safety reasons; or because their type of MS does not respond to some of the treatments available.

2. **Keep Up To Date**

New medicines are being developed all the time, make sure you are aware of the latest approved MS treatments as well as those in the pipeline. This includes both DMTs and those to manage symptoms. When a new drug is licensed the European & Irish Medicines Boards will advise which types of people with MS are eligible for the drug and

your doctor or neurologist can only prescribe the drug within this license.

3. **Weigh Up The Pros And Cons**

To make an informed choice, you need to compare the risks and benefits of different treatment options before deciding to undergo treatment. These resources should help you to identify a range of MS medicines, including the pros and cons of each, and to understand the choice of treatments potentially available to you when talking to your consultant neurologist or MS Nurse Specialist.

4. **Shared Decision Making**

When determining what treatment is right for you it is important for you to talk through any decision with your Consultant Neurologist and MS Nurse Specialist. Key questions you may decide to ask could include:

- What are my options?
- What are the risks and benefits associated with those options?
- How likely am I to be affected by the risks and/or benefits associated with those options?
- The answers to these questions should help you in consultation with your consultant and or your MS Nurse Specialist determine which treatment is the right one for you.

MS medicines approved for use

What are Disease Modifying Treatments (DMTs)?

Managing and treating MS is a combination of many things. Medically, it is about working with health professionals to find suitable treatments and interventions that can keep you as healthy and active as possible. This may include pharmaceutical products, physiotherapy techniques, services or equipment or practical daily living strategies.

Socially, it is about finding ways to maintain participation in society through your home life, work, leisure pursuits and community activity. Emotionally, it is about finding ways to cope with challenges and maintain good mental health.

DMTs are drugs that can modify or change the course of a disease and are merely one part of the treatment and management process, but deciding which drug – if any – to go on can be a difficult task for PwMS. One of the aims of this Handbook is to provide you with information about each of the DMTs on the market at present. We also look at potential treatments that could be coming online very shortly.

While you may not decide to go on medication immediately after your diagnosis, it is important that you have a discussion about potential DMT options soon after diagnosis. There are a number of factors to consider, including the benefits and risks of starting or delaying treatment, as well as how taking the drugs will affect your life. It will also be important to understand whether your Hospital provides access to all approved and available treatments as some Hospitals may restrict access to new innovative therapies for budget reasons.

So how do DMTs work and why are people with relapsing remitting MS benefiting most?

There has been no cure developed for MS but a series of effective drug treatments have been developed. The drugs currently available interact with different parts of the immune system to calm down the inflammation that causes MS. These treatments may offer a reduction in relapse rates, reduce hospitalisations and or slow the progression of disability.

Going on a DMT is a long-term commitment for people with MS, but it is not necessarily a lifelong one. Your neurologist should regularly review your treatment, and talk to you about changing or stopping treatment if a more suitable or effective treatment option is available or if the treatment you are receiving is not adequately controlling the condition.

It is important to remember that everybody's experience of DMTs will be different. What is right for one person may not be right for someone else. Different people will have different reactions to certain drugs. Some people will have no reactions, as you will see in our case studies later on pages 32 and 33. Also just because a drug is new does not mean it is better or will work better for you so if you are on a drug which is controlling your MS very well there is no reason to change just because new options become available.

Which DMTs are available here in Ireland?

So far, 12 DMTs and one MS specific symptomatic treatment have been licensed and are available in Ireland. These are:

Summary of medicines					
Trade Name	Drug Company	Active Substance	Line of Treatment	DMT	Year of Authorisation
Aubagio	Genzyme	Terflunomide	1st	Yes	2013
Avonex	Biogen	Beta Interferon-1a	1st	Yes	2003
Betaferon	Bayer	Beta Interferon-1b	1st	Yes	1995
Copaxone 20mg/ml	Teva	Glatiramer Acetate	1st	Yes	2001
Copaxone 40/mg/ml	Teva	Glatiramer Acetate	1st	Yes	2015
Extavia	Novartis	Beta Interferon-1b	1st	Yes	2008
Fampyra	Biogen	Ampridine	N/A - Symptomatic therapy	No	2011
Gilenya	Novartis	Fingolimod	2nd *	Yes	2011
Lemtrada	Genzyme	Alemtuzumab	2nd *	Yes	2013
Plegridy	Biogen	Peginterferon beta-1a	1st	Yes	2014
Rebif	MSD	Beta Interferon-1a	1st	Yes	2011
Tecfidera	Biogen	Dimethyl Fumarate	1st	Yes	2014
Tysabri	Biogen	Natalizumab	2nd *	Yes	2006

**** May be given first line if certain criteria for highly active MS are met.***

Prescribing DMTs in Ireland

First-line treatments

Aubagio, Avonex, Betaferon, Copaxone, Extavia, Lemtrada, Plegridy, Rebif, and Tecfidera are all first-line therapies available for MS. They are prescribed to those with relapsing remitting MS who have experienced a minimum of two significant relapses in the past two years, as well as children and young people with relapsing remitting MS. People with secondary progressive MS who are still experiencing relapses can also be prescribed the first-line therapies.

DMTs are administered differently, some are self-injected once to several times per week, some are oral tablets, some by monthly infusion and some are administered in two treatment cycles a year apart. The efficacy and safety of these drugs has been established through a series of clinical trials and they have all met the required regulatory requirements for use in Ireland.

MS medicines approved for use

Second-line treatments

Gilenya, Lemtrada and Tysabri are considered to be second-line treatments because they are prescribed to people with very active MS or who have failed treatment with the first line drugs, and come with potentially greater side effects than other first-line treatments.

Symptomatic treatments

Whilst not a DMT, Fampyra is a medicine that is used to manage some of the symptoms of MS and is indicated for symptomatic improvement of walking and mobility for PwMS who have established mobility problems.

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
Aubagio	Aubagio is indicated for the treatment of adults with RRMS.	It reduces the number of relapses by up to 36%. Aubagio helps to protect against attacks on the central nervous system by the immune system by limiting the increase of some white blood cells (lymphocytes). This limits the inflammation that leads to nerve damage in MS.	Once daily	Oral tablet taken once daily.	<p>Very common side effects (may affect more than 1 in 10 people):</p> <ul style="list-style-type: none"> - Diarrhoea, feeling sick - Increase in ALT (increase in blood levels of certain hepatic enzymes) shown in tests - Hair thinning <p>Common side effects (may affect up to 1 in 10 people):</p> <ul style="list-style-type: none"> - Influenza, upper respiratory tract infection, urinary tract infection, bronchitis, sinusitis, sore throat and discomfort when swallowing, cystitis, gastroenteritis viral, oral herpes, tooth infection, laryngitis, fungal infection of the foot - Low level of white blood cells - shown in tests and a decrease in the number of red blood cells (anaemia) - Mild allergic reactions - Feeling anxious - Pins and needles, Feeling weak, numb, tingling or pain in the lower back or leg (sciatica); feeling numb, burning, tingling or pain in the hands and fingers (carpal tunnel syndrome) 	Hi-Tech Scheme

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
					<ul style="list-style-type: none"> - Increase in blood pressure - Being sick (vomiting), toothache, upper abdominal pain - Rash, acne - Pain of the tendons, joints, bones, muscle pain (musculoskeletal pain), - Needing to urinate more often than usual - Heavy periods - Pain - Changes in liver and white blood cell test results - Weight loss 	
Avonex	Adults and adolescents aged 12 years and over diagnosed with relapsing MS or with a single demyelinating event and at high risk of developing MS	Slows the progression of disability and decreases the frequency of relapses.	Once a week	Into a muscle, e.g. upper thigh.	Very common side effects (at least 1 in 10 people affected) include flu-like symptoms and headache.	High-Tech Scheme
Betaferon	<p>People with a single demyelinating event with an active inflammatory process, if it is severe enough to warrant treatment with intravenous corticosteroids, if alternative diagnoses have been excluded, and if they are determined to be at high risk of developing clinically definite multiple sclerosis</p> <p>People with Relapsing Remitting MS</p> <p>People with secondary Progressive MS who still mobilise</p>	Delay in the progression from first clinical event to Clinically Definite Multiple Sclerosis (CDMS) Reduction in frequency and severity of clinical relapses, as well as the number of hospitalisations due to disease. Prolongation of the relapse-free interval. Delay of disease progression Reduction in the frequency of relapses	Every second day hospitalisations due to disease. Prolongation of the relapse-free interval. Delay of disease progression Reduction in the frequency of relapses	Subcutaneously (under the skin)	At the beginning of treatment adverse reactions are common but in general they subside with further treatment. The most frequently observed adverse reactions are a flu-like symptom complex (fever, chills, arthralgia, malaise, sweating, headache, or myalgia) and injection site reactions.	High-Tech Scheme

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
COPAX-ONE® 20mg/ml	People with Relapsing Remitting Multiple Sclerosis (RRMS) and people who have experienced a well-defined first clinical episode and are determined to be at high risk of developing clinically definite multiple sclerosis (CDMS)	Copaxone 20 mg/ml is used to reduce the number of times you suffer attacks of MS (relapses)	To be taken daily	COPAXONE®20mg/ml is injected subcutaneously. There are seven possible areas on your body for injection: arms, thighs, hips and stomach (belly). Within each injection area there are several injection sites.	<p>Like all medicines, COPAXONE® can cause side effects, although not everybody gets them.</p> <p>Allergic reactions (hypersensitivity) You may rarely develop a serious allergic reaction to this medicine. Stop using Copaxone 20 mg/ml and contact your doctor immediately or go to the casualty department at your nearest hospital, if you notice any sign of these side effects:</p> <ul style="list-style-type: none"> • rash (red spots or nettle rash) • swelling of the eyelids, face or lips • sudden shortness of breath • convulsions (fits) • fainting <p>Other reactions following injection (immediate post-injection reaction) It's uncommon but some people may get one or more of the following symptoms within minutes after injecting Copaxone 20 mg/ml. They normally do not cause any problems and usually disappear within half an hour. However, if the following symptoms last longer than 30 minutes, contact your doctor immediately or go to the casualty department at your nearest hospital:</p> <ul style="list-style-type: none"> • flushing (reddening) of the chest or face (vasodilatation) • shortness of breath (dyspnoea) • chest pain • pounding and rapid heartbeat (palpitations, tachycardia) 	

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
COPAX-ONE® 20mg/ml					<p>The following side effects have been reported with COPAXONE® 20mg/ml as very common (may affect more than 1 in 10 people)</p> <ul style="list-style-type: none"> • infection, flu • anxiety, depression • headache • feeling sick • skin rash • pain in the joints or back • feeling weak, skin reactions at the injection site including reddening of skin, pain, formation of wheals, itching, tissue swelling, inflammation and hypersensitivity (these injection site reactions are not unusual and normally decrease over time), non-specific pain 	
COPAX-ONE® 40mg/ml	People with Relapsing Multiple Sclerosis (RMS)	Copaxone 40 mg/ml is used to reduce the number of times you suffer attacks of MS (relapses)	To be taken three times per week (with a minimum of 48 hours between injections)	COPAXONE®40mg/ml is injected subcutaneously. There are seven possible areas on your body for injection: arms, thighs, hips and stomach (belly). Within each injection area there are several injection sites.	<p>Like all medicines, COPAXONE® 40mg/ml can cause side effects, although not everybody gets them.</p> <p>Allergic Reactions (hypersensitivity) You may develop a serious allergic reaction to this medicine but it is uncommon.</p> <p>Stop using Copaxone 40 mg/ml and contact your doctor immediately or go to the nearest hospital casualty department, if you notice any sign of these side effects:</p> <ul style="list-style-type: none"> • rash (red spots or nettle rash) • swelling of the eyelids, face or lips • sudden shortness of breath • convulsions (fits) • fainting 	High-Tech Scheme

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
COPAX-ONE® 40mg/ml					<p>Other reactions following injection (immediate post-injection reaction)</p> <p>Some people may get one or more of the following symptoms within minutes after injecting Copaxone 40 mg/ml. They normally do not cause any problems and usually disappear within half an hour.</p> <p>However, if the following symptoms last longer than 30 minutes, tell your doctor immediately or go to the casualty department at your nearest hospital:</p> <ul style="list-style-type: none"> flushing (reddening) of the chest or face (vasodilatation) shortness of breath chest pain pounding and rapid heartbeat (palpitations, tachycardia) <p>In general the side effects reported by people using COPAXONE® 40 mg/ml three times a week were also reported in people who used COPAXONE® 20 mg/ml (see the following list). Very common (may affect more than 1 in 10 people)</p> <ul style="list-style-type: none"> infection, flu anxiety, depression headache feeling sick skin rash pain in the joints or back feeling weak, skin reactions at the injection site including reddening of skin, pain, formation of wheals, itching, tissue swelling, inflammation and hypersensitivity (these injection site reactions are not unusual and normally decrease over time), non-specific pain 	

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
Gilenya	People whose neurologist considers that their disease is rapidly evolving	54% relapse rate reduction but also benefits on disability, MRI and brain atrophy (67% reduction if only highly active patients were analysed but the study was not specifically designed for this group)	Once daily	Not injected - oral	The 5 main safety areas of interest are: Bradycardia (slowing heart rate) on first dose, Macular oedema (an eye problem) for which you will be examined for within 3 to 4 months of initiating Gilenya, Low lymphocyte count due to the mechanism of action of Gilenya Raised liver enzymes, which will be checked by a blood test Gilenya should not be taken if you are pregnant or planning to become pregnant	High-Tech Scheme
Lemtrada	Lemtrada is indicated for adult people with RRMS with active disease defined by clinical or imaging features.	In clinical studies, people treated with Lemtrada had fewer relapses and were less likely to experience worsening of their disability compared to people treated with a beta-interferon injected multiple times per week. In two trials, median brain volume loss was reduced after Lemtrada vs. a beta-interferon injected multiple times per week Lemtrada works by targeting a protein called CD52 found on the surface of immune cells. Lemtrada adjusts the immune system to limit future attacks on the nervous system. Lemtrada does not cure MS, but it can reduce the number of MS relapses. It can also help to slow down or reverse some of the signs and symptoms of MS.	Administered in two treatment courses. For the first treatment course people receive one infusion per day for 5 days (course 1). One year later, people receive one infusion per day for 3 days (course 2). There is no Lemtrada treatment between the two courses.	Infusion	Common side effects (more than 1 in 100): Thyroid disorders can be common Less common: (less than one in 100): Idiopathic Thrombocytopenic Purpura is a disorder that prevents blood from clotting. Kidney disease (such as anti-GBM disease, an autoimmune problem with the kidneys) is also a major side effect (rare – may affect up to 1 in 1,000 people).	Approved for reimbursement in hospitals.

First-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
Plegridy	Adults with relapsing remitting MS.	Slows the progression of disability and decreases the frequency of relapses.	Once every 2 weeks	Under the skin of the thigh, abdomen or upper arm.	Very common side effects (at least 1 in 10 people affected) include flu-like symptoms, headache, muscle pain, pain in joints/arms/legs/neck, chills, fever, feeling weak and tired, and injection site reactions.	High-Tech Scheme
Rebif		Rebif has been shown to reduce the number and the severity of relapses and to slow the progression of disability. It is also approved for use in patients who have experienced a single clinical event likely to be a first sign of multiple sclerosis. Rebif has an established long term efficacy and safety profile.			Common side effects (more than 1 in 100) include flu-like symptoms, injection site reactions, liver enzyme abnormalities, headache, depression, nausea or vomiting, difficulty sleeping and hair loss. Less common effects (less than one in 100) can include thyroid dysfunction, allergic reactions, liver inflammation, increased sweating and blood clots.	
Tecfidera	Adults with relapsing remitting MS.	Slows the progression of disability and decreases the frequency of relapses.	Twice a day	N/A, capsule for oral administration.	Flushing and gastrointestinal effects. Very common side effects (at least 1 in 10 people affected) include flushing, diarrhoea, nausea and stomach pain/cramps.	High-Tech Scheme
Tysabri	Adults with highly active rapidly evolving severe relapsing remitting MS.	Disabling effects of MS approximately halved and the number of MS attacks decreased by about two-thirds in clinical trials.	Once a month	Infusion into a vein, usually in the arm	Very common side effects (at least 1 in 10 people affected) include infusion reactions, e.g. dizziness, feeling sick, itchy rash and shivering. Progressive multifocal leukoencephalopathy (PML) is an uncommon but serious side effect.	Approved for reimbursement in hospitals.

Second-line therapies

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
Gilenya	People who have failed on a first line treatment	In clinical studies, people treated with Gilenya had fewer relapses, reduction in the number and size of MRI lesions, reduction in brain volume loss and were less likely to experience worsening of their disability compared to people treated with interferon	Once daily	Orally	Over 114,000 people have taken Gilenya so we know a lot about the side effects. The 5 main safety areas of interest 1. Bradycardia (slowing heart rate) on first dose. 2. Macular oedema (an eye problem) for which you will be examined for within 3 to 4 months of initiating Gilenya. 3. Low lymphocyte count due to the mechanism of action of Gilenya. 4. Raised liver enzymes, which will be checked by a blood test. Gilenya should not be taken if you are pregnant or planning to become pregnant	High-Tech Scheme
Tysabri	Adults with relapsing remitting MS who have high disease activity despite treatment with interferon or glatiramer acetate.	Disabling effects of MS approximately halved and the number of MS attacks decreased by about two-thirds in clinical trials.	Once a month	Infusion into a vein, usually in the arm	Very common side effects (at least 1 in 10 people affected) include infusion reactions, e.g. dizziness, feeling sick, itchy rash and shivering. Progressive multifocal leukoencephalopathy (PML) is an uncommon but serious side effect	Hospital budgets

Symptomatic treatments

Drug	Who takes it?	What are the benefits?	How often do I take it?	How is it taken?	Possible side effects	How is it reimbursed?
Fampyra	Adults with MS related walking disability.	Walking speed improvement	Twice a day	Tablet for oral administration	Very common side effects (at least 1 in 10 people affected) include urinary tract infection.	People who are prescribed Fampyra must self fund *

Are there other potential treatments on the way?

People with MS could soon have access to new drugs in the future. These would include certain opiate antagonists, cannabinoids and medicines that are in development. More information can be found at www.ms-society.ie

* Up to August 2015 people who were prescribed Fampyra must self-fund. On September 2nd 2015 the HSE confirmed that 'it is in the final stages of putting in place the governance arrangements and processes around a responder based reimbursement programme for Fampridine. For up to date information please visit our website www.ms-society.ie

Access to MS Medicines in Ireland

How are MS medicines made available in Ireland?

In Europe, all drug companies must apply to the European Medicines Agency (EMA) for licensing of their drugs. Once the EMA has granted a license for a specific drug the Health Products Regulatory Authority (HPRA) approves the licence for the Irish market. At this point the drug company who is the producer of the drug can formally request the HSE to consider reimbursing the drug and making it available to PwMS in the Irish health system.

To assess whether the drug should be reimbursed or not the HSE requests the National Centre Pharmacoeconomics (NCPE) to carry out a cost benefit analysis and or a Health Technology Assessment (HTA) on the drug to assess its cost effectiveness. The NCPE then makes a recommendation in conjunction with the HSE's Corporate Pharmaceutical Unit (CPU) as to whether the drug should be reimbursed or not. If the HSE decides not to reimburse the drug, the Minister for Health can still overrule this decision ensuring that the drug will be reimbursed in the Irish health system.

If an MS treatment does not receive NCPE approval, it will not usually be reimbursed by the HSE. It will only be possible for people with MS to access a treatment with a 'no' decision from the NCPE if it is paid for privately or a clinician believes that the drug would be effective and if the hospital is willing to pay for the treatment through an individual funding request and out of its own budget, but this is unusual. Therefore, the likelihood of a hospital granting access to a medicine that the NCPE has decided is not cost-effective is seriously reduced unless individual circumstances prove to be exceptional.

In certain circumstances drugs can be made available to PwMS pending a licensing and or reimbursement decision. This can be done on a "Named PwMS Basis" and may relate to drugs being used in a clinical trial or where a drug meets an unmet clinical

need. This requires HPRA approval.

Drug Companies may also agree to establish Early Access Programmes or Compassionate Access Programmes when a drug has been licensed but before it has been officially launched or a decision on reimbursement has been taken. These programmes are designed to provide treatment to PwMS early where there is an otherwise unmet clinical need. These can be established where the Drug company offers the drug for free, subsidises the cost of the drug or agrees a price with the relevant health authorities. All of these programmes require the advance approval of the HPRA

Who are the main players and influencers in deciding what treatments can be used in Ireland?

The European Medicines Agency

The EMA was set up in 1995 with funding from the European Union and the pharmaceutical industry, as well as indirect subsidy from member states, in an attempt to harmonise (but not replace) the work of existing national medicine regulatory bodies. The EMA considers scientific evidence including clinical trial data and other academic research when making decisions on licensing.

The Health Products Regulatory Authority

The HPRA was formerly known as the Irish Medicines Board (IMB) and grants licenses to companies to make, distribute and market medicines after a review of their safety, quality and effectiveness. HPRA continuously monitors medicines, medical devices and other health products once they are available on the market and responds quickly to any safety or quality concerns. This includes operating national reporting systems, which allows people to report safety and quality issues directly to HPRA.

The HPRA produces safety and quality information on health products for PwMS and healthcare professionals to support their safe use. The HPRA

Access to MS Medicines in Ireland

also inspects companies and facilities, which test, make or distribute health products to ensure that they comply with relevant standards and legislation. The HPRA also contributes to regulatory committees and working parties at a national, European and global level for all products under their remit.

The Health Services Executive

The HSE functions as a single national agency delivering health services in Ireland. Senior figures from the HSE sit on the HSE Drugs Group which considers the recommendations of the NCPE and CPU as to whether a drug should be reimbursed or not. Once it is agreed that a drug will be reimbursed, the HSE will then determine how the drug will be reimbursed.

The National Centre For Pharmacoeconomics

The NCPE was established in 1998 and is funded by the Department of Health. Activities of the Centre include economic evaluation of pharmaceutical products and the development of cost effective prescribing. In addition, the research of the Centre focuses predominantly on the economic analysis of high cost areas. In collaboration with the CPU, the NCPE now considers the cost effectiveness of all new medicines following receipt of an application for reimbursement and makes a recommendation on reimbursement to the HSE on that basis.

Corporate Pharmaceutical Unit

Within the HSE, the CPU is responsible for pricing, reimbursement and the provision of drugs and devices for PwMS. The CPU works with the NCPE to determine whether a drug is cost effective or not and on that basis makes a recommendation to the HSE as to whether the drug should be reimbursed or not.

The Department of Health (DoH)

The DoH supports the Minister for Health and the Government by advising on the strategic development of the health system including policy and legislation and evaluating the performance of

the health and social services. The Department may become involved in access and reimbursement issues and advises the Minister of Health on that basis.

The Minister for Health

The Minister for Health has overall political responsibility for the DoH. Ultimately it is the Minister who signs off on all major decisions made in the health system and it is the Minister and his Department who are accountable to the Dail for health spending and have the final say on the reimbursement of medicines in the Irish system.

The Health Information and Quality Authority (HIQA)

HIQA conducts system wide HTAs and sets guidelines on HTAs that are used by the NCPE. It was established in May 2007 as an independent authority reporting to the Minister for Health.

Private Health Insurers

There are currently four private health insurance companies in the Irish market and these are; VHI, Laya Healthcare, Aviva and GloHealth. These companies make their own decisions with regard to what treatments and drugs they reimburse for their customers. To understand what your private health insurance company reimburses, MS Ireland advises that you contact them directly.

Access to MS Medicines in Ireland

How can people publically access MS Medicines in Ireland?

People with long-term illnesses in Ireland are eligible for a nominated list of approved drugs under a range of schemes and funding mechanisms that are described below. This is particularly true for treatments that are provided in the community. MS is classified by the HSE as a long-term illness. Certain drugs such as Tysabri and Lemtrada, which are administered in the hospital, are not covered by these community schemes but reimbursed by the administering hospital. Reimbursement remains a thorny issue as health budgets remain under pressure. This means that the HSE has become more reluctant to reimburse new drugs or solve issues with hospital-delivered drugs. Drugs such as Lemtrada or Tysabri which are administered in hospitals, are funded by the hospitals directly. Many hospitals reduce or refuse access to innovative medicines to contain their expenditure. This may lead to geographic discrimination for PwMS. If you are considered suitable for these treatments, then ask your Consultant if there are any financial restrictions in your hospital that will limit your access to treatment.

What public funding mechanisms can people with MS avail of?

Currently, PwMS may be able to avail of treatments and medical services through the following publicly funded schemes:

1. Long Term Illness Scheme

If you have MS, you should apply to join the Long Term Illness (LTI) Scheme and you will be supplied with a Long Term Illness book. This book allows you to get some medicines, as well as medical and surgical appliances directly related to the treatment of your MS, free of charge. It does not depend on your income or other circumstances and is separate from the Medical Card Scheme and the GP Visit Card Scheme.

2. High Tech Scheme

Arrangements are in place for the supply and

dispensing of High Tech medicines through community pharmacies. Such medicines only prescribed or initiated in a hospital and include most MS drugs and other treatments. The medicines are purchased by the Health Service Executive (HSE) and supplied through community pharmacies for which pharmacists are paid a PwMS care fee: the cost of the medicines and PwMS care fees are paid by the HSE.

3. Funding available through Hospital Budgets

When the HSE approves reimbursement of products that are administered in hospitals, it is the responsibility of the hospitals to provide such products when prescribed by a consultant. We are aware of many instances where hospitals have refused or restricted access to treatment in order to contain costs, this leads to a postcode lottery effect. If a medicine is licensed and approved for reimbursement, it should be available to all PwMS based on clinical need. It should not be at the discretion of hospital management as to whether it is made available or not based on local budgetary considerations as to whether medicines are made available. Critical influencers in a hospital around this issue are hospital management, hospital pharmacists and clinical directors.

4. Medical Card Scheme

People who are unable without undue hardship to arrange general practitioner medical and surgical services for themselves and their dependents are entitled to receive a medical card. Normally dependent spouses or partners and children are also covered for the same range of health services. To qualify for a medical card, the person's weekly income must be below a certain figure for their family size.

5. GP Visit Card Scheme

People who do not qualify for a Medical Card on income grounds may be entitled to a GP Visit Card. More detail on this is available on HSE website

www.hse.ie/eng/services/list/1/schemes/mc/gpvc

How to ‘Get Loud’

If your consultant has indicated that you would benefit from a licensed treatment but you cannot actually get access to the treatment, you can challenge this by following MS Ireland’s 9-step plan on how to ‘Get Loud’. Each of the 9 steps is detailed below and supporting template letters can also be found on pages 34 – 39.

Remember that others have done this before and succeeded, so do not lose hope if a local resolution does not work.

Step 1: Seek clarification and support from Health Care Professionals

If you have a problem accessing an MS treatment, local health care professionals in your area including your neurologist or MS nurse may be able to assist you. In the first instance it will be important for you to understand:

- What treatment is being recommended to you.
- Why it is being recommended to you.
- Why are other treatment options not being recommended to you.

To do this you should:

- Contact your local GP, and or pharmacist, to understand the process of obtaining treatments in Ireland, how these treatments can be sourced and the reimbursement schemes available for MS treatments.
- Talk to your consultant neurologist or MS nurse about helping you, and ask about any local issues. It is important to identify the particular reasons why the medicine is not available in your area, so that you can address these directly. In the Health Information Quality Authority (HIQA’s) ‘Standards for Safer Better Healthcare’, it is stated that “service users’ complaints and concerns are responded to promptly, openly and effectively with clear communication and support provided throughout this process”. It is therefore best to address any concerns over the quality of your treatment with your consultant neurologist before elevating your complaint to a

higher authority.

You can find a template letter and further guidance for writing to your health care provider at the end of this handbook (Template letter A)

Step 2: Seek support from MS Ireland

If you have a problem accessing an MS medicine, the chances are it is also an issue for other people with MS in your area.

- Your local MS Ireland regional office or support team might know of people with the same problem in your area.
- Through your local MS Ireland regional office you can access a wide range of information via one of MS Ireland’s services. Through these services, you will be able to evaluate your position and provide guidance on the next course of action.

You can contact MS Ireland on the MS Information Line 1850 233 233 or email info@ms-society.ie.

Step 3: If the drug is a hospital funded drug recommended by your neurologist but the hospital has refused to approve it then make a formal complaint to the Hospital Management but ensure you follow local procedures.

If you have the support of a healthcare professional and they make representations on your behalf to hospital management to help you gain access to a MS treatment, you can support this process by submitting a letter to the relevant hospital manager. It will also be important to ask your hospital for a copy of its complaints procedure. Remember, usually a complaint must be made within 12 months of the event you are complaining about occurring.

Often, a complaint is written as a letter to the Chief Executive of the hospital, the hospital’s clinical director and / or the hospital pharmacist. To make quite sure it gets logged as an official complaint, copy your letter into the ‘Your Service, Your Say’ complaint form used by the HSE. This is part of an official overall drive by the HSE to improve its own customer responsiveness.

How to ‘Get Loud’

You can find a template letter and further guidance for writing to your hospital at the end of this handbook (Template letter B).

A step-by-step guide on how to complain can be found on the HSE website or, alternatively, more information can also be found on the Citizens Information website.

Some handy tips!

1. Keep your complaint succinct – only explain what is necessary.
2. You may find it helpful to detail events chronologically – this will help you structure your complaint.
3. Attach any supporting evidence such as letters, emails and any relevant notes to the end of the form.

Step 4: Make a formal complaint to the HSE and / or the Department of Health

Make a formal complaint to the HSE through the ‘Your Service, Your Say’ facility within the HSE. For maximum impact send a copy of your complaint to the Director General of the HSE and or the National Director of Acute Hospitals

Request a meeting with a senior official to help you resolve your complaint.

If they will not do this, and do not address your concerns in writing to your satisfaction, then it is time to involve your local political representative(s).

You can find a template letter and further guidance for writing to the HSE/Department of Health at the end of this handbook (Template letter C).

Step 5: Contact your local Teachta Dála (TD) or Senator(s)

TDs can put pressure on the hospital and on Government ministers regarding your situation. With your permission, they can help promote your case in the media and raise it in the Houses of the

Oireachtas. More importantly, they might act on your behalf and speak directly to the hospital about your case.

Many TDs hold consultation clinics where constituents can raise their particular local issues. There is no substitute for a face-to-face meeting with a TD – no matter how brief. So if you can arrange a time to meet them, it is worth doing. Remember to keep in touch with your TD and let them know if your situation changes. Visiting your TD during a constituency surgery is really easy to do but if you find the experience of visiting your TD in person daunting, then by contacting MS Ireland, a volunteer can assist you in your visit to your TD. Find your local TD by entering your postcode on the Dáil website to <http://www.oireachtas.ie/members-hist/default.asp?housetype=0&HouseNum=31&disp=mem> or call the Houses of the Oireachtas on 00 353 (0)1 6183000 or 076 1001700.

If you are still facing issues the TD may suggest elevating the matter to the Oireachtas Sub-Committee for Health.

You can find a template letter and further guidance for writing to your TD or Senator at the end of this handbook (Template letter D).

Step 6: Contact the Dail Sub-Committee on Health

If you have a problem accessing an MS medicine, contacting the Dail Sub-Committee on Health is an effective way to raise awareness about any discriminatory practices that impact on you being able to access appropriate treatment. By raising your issue to the Dail Sub-Committee, your case will be reviewed in respect of public policy of MS treatments, with a context of statutory obligations. The Dail Sub-Committee is important as it contains representation from all of the major political parties in the State as well the main opposition parties spokespeople for Health.

Remember to keep in touch with your TD when contacting the Dail Sub-Committee on Health and let them know if your situation changes. If you fail to

How to ‘Get Loud’

receive an adequate response to your request, it is time to start considering briefing the local press. A full list of Sub-Committees members can be found at http://www.oireachtas.ie/parliament/oireachtasbusiness/committees_list/health-and-children/subcommittee-health/

You can find a template letter and further guidance for writing to the Chair of the Dail Sub-Committee on Health at the end of this handbook (Template letter E).

Step 7: Share your MS story with the media

Involving the media in your campaign to access MS medicines can be a good way to create greater awareness of the issue and put pressure on hospitals to fulfill their clinical obligations to PwMS, but the media spotlight might not be for everyone. Journalists will want to know your full name, age, where you live and specific details about your MS – so it is important to consider this before going down this route.

If you feel you may want to share your story with the media, you should consider the following guidance:

- Telling your story in the media should be a last resort in your campaign; your story will be stronger if you have already taken all reasonable steps to raise the issue with your medical professionals and the hospital. Going to the media too soon may be counter-productive, but if you have taken these steps and have still been frustrated in your efforts to access an MS medicine, then approaching the media may be appropriate and can be very powerful.
- At MS Ireland, we always need strong examples of injustice to strengthen our campaigning, so we would be happy to speak to you about your story before you contact the media. In the first instance, you should contact the Communications team. It may be that

your story highlights a wider issue, and our Communications team may be able to support you in speaking to the media on this basis.

- If you decide to contact the media directly, you should think through the key points of your story before you make contact. It is usually helpful to think about the five Ws: what, when, who, where and why. It is not necessary to attempt to write a ‘press release’; a short email summarising your case should suffice, perhaps followed up by a phone call to the news desk of the newspaper or radio station you want to approach. Ensure you give them your full contact details so that they can call you back.
- Before you speak to any journalists, it is a good idea to be prepared: write down what it is you want to say, the message you want to get across and stick to the main points.

It may be helpful to involve your local TD. They can help generate interest in a story and support your case in the media.

Step 8: Take it to the next level – the Ombudsman

If you have sought local resolution, and got your local TD and press on board, and still no progress is being made, it is time to take things to the next level – the Ombudsman.

A carer or relative can make the complaint to the Ombudsman on your behalf.

The Ombudsman is independent of the HSE and Government. The Ombudsman has a duty to investigate further if you can show that the HSE has not acted properly or fairly (or has not provided a good service).

How to ‘Get Loud’

To get the Ombudsman to take up your case, you must have:

- Already submitted a complaint to your local hospital.
- Gone through all the appeals and local resolution opportunities the hospital provides then you need to complete a short form. This will ask:
 1. *For information on the original complaint and why you are unhappy.*
 2. *How you have been affected, and what you would like to happen.*
 3. *Do not forget to attach any supporting evidence. This includes letters, emails, records of meetings, and notes you have made about the situation.*

The Ombudsman does not have to investigate every complaint. You will need to make it clear how your complaint fits within the scope of the Ombudsman's duties.

The Ombudsman can investigate if:

- There is evidence of administration fault or service failure and there has been injustice or hardship caused as a result.

If you can show how your case meets these criteria, the Ombudsman may investigate the case with the HSE. Alternatively, he might intervene before investigating if it is considered that the evidence is so clear that the Ombudsman can seek resolution directly.

Details of the procedure and a complaints form are available on the Ombudsman website:

www.ombudsman.gov.ie/en/publications/information-leaflets/the-ombudsman-and-the-health-service-executive/

If you do not have access to a computer, call 1890 22 30 30 for further information and request a hard copy.

Step 9: Seek judicial review

A judicial review is a type of court proceeding. A judge reviews the decision or action made by a public body, in this case a primary care hospital, and decides if it was lawful.

A judicial review challenges the way in which a decision has been made, rather than the rights and wrongs of the conclusion reached.

You can only challenge a decision in this way if it was:

- Illegal
- The procedure was unfair
- The decision was so unreasonable that no reasonable public body could have taken it

Case Studies

Natalie (DUBLIN)

HOW THE CAMPAIGN STARTED

In March 2015 Natalie was told by her consultant neurologist that Lemtrada (alemtuzumab) may be a suitable treatment option for her. However, Natalie was informed that she could not access Lemtrada at the hospital she was attending as the quota for dispensing this drug to patients had already been met. As Natalie is 25 years old and lives on her own, it is vital to her that she receives the correct medicine which will allow her to retain her independence and manage her MS.

WHAT HAPPENED NEXT?

Natalie sent letters pleading her case to her local TDs, health representatives at the hospital and the Health Service Executive (HSE).

The letters acted to remind local TDs and the HSE that Lemtrada is a licensed treatment with the efficacy and safety having been reviewed and approved by the relevant authorities. Natalie also highlighted other relevant points about her case, it is unfair to deny her a medicine based on where she lives or what hospital she attends and that the cost to the HSE in the long-term if she was not provided with this medicine could be significantly higher.

SUCCESS!

One of the TDs Natalie contacted promised to highlight her case with the Minister for Health. As a direct result of this, on the 30th April 2015 Natalie received a letter from the HSE confirming that her hospital now had approval to prescribe Lemtrada to her.

SHARON (MAYO)

HOW THE CAMPAIGN STARTED

Sharon had been receiving Fampyra, a drug for the symptomatic treatment of walking impairment in adults with MS, for free on a named patient basis up until July 2014. In April 2014 the HSE announced that due to a recommendation from the

National Centre for Pharmacoeconomics (NCPE), Fampyra had been deemed not cost-effective at the submitted price by the pharmaceutical company, Biogen Idec. The HSE stated it would not be reimbursed under any of the payment schemes. Sharon, along with other people with MS wishing to continue to use this drug, would now face a personal cost of between €200-€400 per month.

WHAT HAPPENED NEXT?

Sharon decided to act as a media spokesperson regarding Fampyra in order to raise awareness for the situation regarding reimbursement. She was interviewed for a report on the current affairs show 'Morning Ireland', RTÉ Radio, where she highlighted the significant improvement to her mobility since she began taking Fampyra. She said along with her bills and mortgage, she simply would not be able to self-fund Fampyra long-term. Biogen Idec, the pharmaceutical company supplying Fampyra, submitted a second application for reimbursement to the HSE in September 2014.

RESULT

Negotiations are still underway regarding Fampyra and a decision about reimbursement has not yet been reached. Sharon like many other people with MS using this medicine are still awaiting a result from the HSE. Sharon is a young mum of four-year-old twin girls and has had to significantly reduce her intake of Fampyra due to the cost of the drug. This has resulted in a deterioration of her mobility and a worsening of her symptoms. Sharon, along with many other people with MS, continues to campaign with the relevant authorities for reimbursement for Fampyra and to make sure this issue remains a key topic of discussion.

Case Studies

ROSALEEN (GALWAY)

HOW THE CAMPAIGN STARTED

Rosaleen had been receiving Fampyra, a drug for the symptomatic treatment of walking impairment in adults with MS for free on a named patient basis up until July 2014. In April 2014 the HSE announced that due to a recommendation from the National Centre for Pharmacoeconomics (NCPE) Fampyra had been deemed not cost-effective at the submitted price by the pharmaceutical company, Biogen Idec. The HSE stated it would not be reimbursed under any of the Payment Schemes. If Rosaleen wished to continue using Fampyra she would now have to self-fund the medicine and faced a personal cost of €275 per month as quoted by her pharmacist.

WHAT HAPPENED NEXT?

Rosaleen sent letters lobbying the Minister for Health, senators and local Galway TDs to approve reimbursement for Fampyra. In the letters Rosaleen highlighted the improvements to her mobility, balance and fatigue which she had experienced since she began taking Fampyra. Rosaleen's daughter Caitriona is a nurse and she started a Facebook campaign called 'Give Me My Meds' which called for public support for Rosaleen as she continued to fight for reimbursement of Fampyra. Rosaleen contacted TV3's current affairs and political programme 'Tonight with Vincent Brown' where her story was featured. She has also been featured in the Irish Times, Irish Daily Mirror and the Connacht Tribune and continues to act as a media spokesperson regarding Fampyra.

RESULT

Negotiations are still underway regarding Fampyra and a decision about reimbursement has not yet been reached. Rosaleen like many other people with MS using this medicine are still awaiting a result from the HSE. Rosaleen has attempted to reduce her dosage of Fampyra as she was struggling to self-fund the drug. She found that after being without the drug for only three days her mobility had deteriorated to the point that she could no

longer do most of the exercises in her weekly physiotherapy class and she was experiencing a large number of falls due to loss of balance and stability. To date Rosaleen's Facebook campaign has over 6,000 followers supporting her and she has received several responses to her ongoing lobbying letters to confirm that the subject is receiving attention from the HSE. Rosaleen plans to continue to lobby the relevant authorities for reimbursement for Fampyra under one of the HSE's payment schemes.

Up to August 2015 people who were prescribed Fampyra must self-fund. On September 2nd 2015 the HSE confirmed that 'it is in the final stages of putting in place the governance arrangements and processes around a responder based reimbursement programme for Fampridine. For up to date information please visit our website www.ms-society.ie

Template Letters

To copy and paste any of the letters below or to download these letters as word documents, please visit:
<http://www.ms-society.ie>

Template Letter A – Seeking Clarification from a Healthcare Professional

Insert Your Name
Insert Your Address

Insert Name of Healthcare Professional
Insert Work Address of Healthcare Professional

Insert Date

Dear (Insert Name of Healthcare Professional),

Following my recent consultation with you, you have prescribed XXXX for my Multiple Sclerosis. However, I understand that there are alternative licensed treatments, which would be clinically indicated for me, but which for a variety of reasons are not available to me in this Hospital. I would like to clarify if, despite the clinical benefits of XXXX, it is not being made available to me in this Hospital for budgetary or reimbursement constraints.

You will appreciate that I am seeking this written clarification as I am keen to explore all possible routes to ensure that I can access optimal treatment for my condition. I would appreciate your support in this matter.

I look forward to receiving your response as soon as possible.

Yours sincerely,

(Insert signature and full name)

Template Letters

Template Letter B – Formal Letter to Hospital Management

Insert Your Name
Insert Your Address

Insert Name of Hospital Manager or Clinical Director or Hospital Pharmacist
Insert Address of Hospital Manager or Clinical Director or Hospital Pharmacist

Insert Date

Dear (Insert Name of Hospital Manager or Clinical Director or Hospital Pharmacist),

As a person with Multiple Sclerosis, I have been advised by my (Consultant Neurologist/GP) that being prescribed (Insert Treatment Name) I would get a clinical benefit from XXXX. I understand from my doctor that funding is not available to access this product. I therefore write to you in support of a request that the appropriate funding be put in place to allow this treatment to be made available to me.

In order to ensure that due process has been observed, I have also completed the Hospital Complaint form and I have copied this letter to the HSE's 'Your Service, Your Say' complaint service.

- Demonstrate here how the treatment would be significantly beneficial to you over other available treatments. If you have tried other treatments, which have not worked/produced side effects, mention this here.
- It is important to highlight the wider impact a treatment can have on your life, for example, the treatment may allow you to be more independent and reduce the need for high level care provision.
- Use this space to write down your concerns – e.g. a lengthy delay might mean you progress beyond the point where you would likely benefit or your symptoms might have a major impact on your quality of life.

I am distressed at being denied a treatment that has been clinically indicated as being suitable for me and I hope Management will reconsider their decision and provide funding for (Insert Treatment Name) in light of this letter.

Yours sincerely,

[Insert signature and full name]

Consider copying your letter to the following key influential people who can help to resolve your case:

CC. Name and address of Consultant Neurologist / GP

CC. Name and address of your local TD

Template Letters

Template Letter C – Formal Letter to the HSE / Department of Health (DoH)

Insert Your Name
Insert Your Address

Insert Name of HSE Director General or DoH Secretary General
Insert Address of HSE Director General or DoH Secretary General

Insert Date

Dear (Name of HSE Director General or DoH Secretary General),

As a person with Multiple Sclerosis, I am extremely concerned that (insert Treatment Name), which is approved by the HSE as a treatment for Multiple Sclerosis, is not being made available to me in (Insert name of Hospital) even though it has been prescribed by my Consultant Neurologist with the support of my GP. Furthermore, I have reason to believe that the decision to deny me access is being made on cost containment grounds. I would therefore like to register this letter as a formal complaint as I have already gone through the local complaints processes without this issue being resolved.

(Insert Treatment Name) is licensed for use in Ireland and was approved by the HSE in (insert date) for PwMS with [insert type of MS] MS. As you will be aware the hospital has a legal obligation to fund the approved treatment. The directions enforcing this provision derive from Section 59 of the Health Act 1970.

The Department of Health has directed that the HSE provide funding and resources for appropriate therapies which are deemed cost effective. This is reinforced by HIQA, which requires HSE appraisals to be automatically incorporated into local hospitals' care delivery. This is further supported by the HSE Constitution, which states that PwMS have the right to access HSE approved medicines where a doctor believes it to be clinically appropriate. I would urge the HSE to review tools developed by the HSE to help organisations implement its guidance on (Insert Treatment Name).

- If you have been told you are eligible for the treatment (or know of others who are eligible) and have been refused, state the reasons you have been told/have heard for the refusal e.g. lack of space within the hospital to set up an infusion unit, lack of capacity in terms of nursing staff to run an infusion unit or lack of resources.
- Use this as an opportunity to state clearly, in a few sentences, your concerns e.g. a lengthy delay could mean that you no longer fulfill the clinical criteria set out by the HSE Constitution.
- If you are an MS Ireland branch member and know of others in your area that are being denied treatment; state this here.

I would appreciate a response detailing why the treatment has not been made available to people with MS in [insert location] area. In the response, I would like you to outline what actions will be taken, how and when this situation will be resolved as soon as possible. I would be happy to discuss my complaint with you personally and I hope this issue will be addressed as a matter of urgency. I would welcome a response within two weeks of receipt of this letter.

Yours sincerely,

[Insert signature and full name]

Template Letters

MS Ireland recommends that you consider copying your letter to the following key influential people who can help to resolve your case:

CC. Name and address of Consultant Neurologist

CC. Name and address of your local TD

CC. Name and address of your Hospital Manager, Hospital Clinical Director and Hospital Pharmacist

To make absolutely sure that your letter is logged as an official complaint, copy and paste your letter into an official 'Your Service, Your Say' complaints form to ensure your letter is registered under the HSE formal complaints procedure. The form should be available on the HSE website.

Don't forget to send a copy of your letter to our policy and campaigns team by emailing: communications@ms-society.ie or send a hard copy of your letter to: MS Ireland National Office, 80 Northumberland Road, Dublin 4.

**Template Letter D –
Formal Letter to your local TD(s) or Senator(s)**

Insert Name of TD/Senator
Insert Address of TD/Senator

Insert Date

Dear (Name of TD/Senator),

My name is (Insert Name) and I live (Insert constituency and address). I am writing as a person with Multiple Sclerosis who has recently been told that a licensed and HSE approved treatment that has been prescribed by my Consultant Neurologist is not available at (Insert Hospital Name) due to cost containment grounds. I have written a formal letter of complaint to the HSE and I include a copy of this correspondence for your records.

- Briefly describe what the medicine is and for what symptom/condition it has been licensed to treat
- Briefly explain how the new treatment may benefit you and if other treatments have not worked or been appropriate for you
- Briefly explain what steps you have taken so far to gain access to the medicine

I am distressed at being denied a licensed treatment by my local hospital when the efficacy and safety has been reviewed and approved by the relevant authorities. (If you are aware that the treatment has been made available to other PwMS in your area or in other areas, then mention this too on the basis that you feel it is potentially unfair to have treatments like this restricted on a regional basis).

In light of this and bearing in mind the problems I face, I now seek your support in asking (Insert name of hospital) to review its decision on the provision of (Insert treatment name). I would be very grateful if you could raise my concerns with the relevant authorities. I look forward to your response and I would be happy to discuss this with you in greater detail if you felt that might be helpful.

Yours sincerely,

[Insert signature and full name]

MS Ireland recommends that you keep this cover letter to a single page

Remember to include copies of key documents from your relevant prior correspondence and documentation

Template Letters

Template Letter E – Formal Letter to the Chair of the Dail Sub-Committee on Health

Insert Name of TD
Dail Sub-Committee on Health
Leinster House
Dublin 2

Insert Date

Dear (Name of TD),

My name is (Insert Name) and I am writing to you in your capacity as Chair of the Dail Sub-Committee on Health. I am a person with Multiple Sclerosis who has recently been told that that a licensed and HSE approved treatment that has been prescribed by my Consultant Neurologist is not available at (Insert Hospital Name) due to cost containment grounds. I have written a formal letter of complaint to the HSE and I include a copy of this correspondence for your records.

- Briefly describe what the medicine is and for what symptom/condition it has been licensed to treat
- Briefly explain how the new treatment may benefit you and if other treatments have not worked or been appropriate for you
- Briefly explain what steps you have taken so far to gain access to the medicine

I am distressed at being denied a licensed treatment by my local hospital when the efficacy and safety has been reviewed and approved by the relevant authorities. (If you are aware that the treatment has been made available to other PwMS in your area or in other areas, then mention this too on the basis that you feel it is potentially unfair to have treatments like this restricted on a regional basis).

In light of this and bearing in mind the problems I face, I now seek your support in asking (Insert name of hospital) to review its decision on the provision of (Insert treatment name). I would be very grateful if you could raise my concerns with the relevant authorities. I look forward to your response and I would be happy to discuss this with you in greater detail if you felt that might be helpful.

Yours sincerely,
[Insert signature and full name]

MS Ireland recommends that you keep this cover letter to a single page
Remember to include copies of key documents from your relevant prior correspondence and documentation

Useful Resources and Links

Citizens Information Board

Ground Floor
George's Quay House
43 Townsend St
Dublin 2
Ireland

Phone Number: 0761 07 9000
Fax Number: 01 605 9099
Email: info@ciboard.ie or eolas@ciboard.ie
Website: <http://www.citizensinformationboard.ie>

Corporate Pharmaceutical Unit

Corporate Pharmaceutical Unit
HSE, Primary Care Reimbursement Service
Exit 5, M50
Finglas
Dublin 11
Ireland

Phone Number: 01 864 7100
Fax Number: 01 834 3589
Email: CPU@hse.ie
Website: <http://www.hse.ie/go/cpu/>

Department of Health

Customer Services Unit
Department of Health
Hawkins House
Dublin 2

Phone Number: 01 635 3000
Email: info@health.gov.ie
Website: <http://health.gov.ie/>

European Multiple Sclerosis Platform

Rue Auguste Lambiotte 144 / 8
1030 Brussels
Belgium

Phone Number: +32 2 669 05 41
Website: <http://www.emsp.org/>

Health Products Regulatory Authority

Kevin O'Malley House
Earlsfort Centre
Earlsfort Terrace
Dublin 2
Ireland

Phone Number: 01 6764971
Fax Number: 01 6767836
Email: info@hpra.ie
Website: <https://www.hpra.ie/>

Health Services Executive

Head Office
Oak House
Millennium Park
Naas
Co. Kildare
Ireland

Phone Number: 045 880400
Fax Number: 1890 200 857
Website: <http://www.hse.ie/eng/>

HSE Quality Improvement Division,

Oak House
Lime Tree Avenue
Millennium Park, Naas
Co. Kildare
Ireland

Phone Number: 045 880 400
Email: mila.whelan@hse.ie
Website: <http://www.hse.ie/eng/services/yourhealthservice/contact/National/>

Irish Pharmaceutical Healthcare Association

Wilton Park House
Wilton Place
Dublin 2
Ireland

Phone Number: 01 661 0018
Fax Number: 01 661 0164
Email: info@ipha.ie
Website: <http://www.ipha.ie/>

Useful Resources and Links

Multiple Sclerosis International Federation

Skyline House
200 Union Street
London
SE1 0LX
United Kingdom

Phone Number: +44 (0) 20 7620 1911

Website: <http://www.msif.org/>

Multiple Sclerosis Ireland

80 Northumberland Road
Dublin 4
Ireland

Phone Number: 01 6781600

Email: info@ms-society.ie

Website: <http://www.ms-society.ie/>

Multiple Sclerosis Trust UK

Spirella Building
Bridge Road
Letchworth Garden City
Hertfordshire
SG6 4ET
United Kingdom

Phone Number: +44 (0) 1462 476700

Free Phone Information Service (within the UK):

0800 032 3839

Fax Number: 01462 476710

Email: info@mstrust.org.uk

Website: <http://www.mstrust.org.uk>

National Centre for Pharmacoeconomics Ireland

National Centre for Pharmacoeconomics
St. James's Hospital
Dublin 8
Ireland

Phone Number: 01 410 3427

Fax Number: 01 473 0596

Email: info@ncpe.ie

Website: <http://www.ncpe.ie/>

Glossary

Aubagio (teriflunomide)

Aubagio is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS).

Avonex (Beta-Interferon 1a)

Avonex is the brand name for a disease modifying treatment for people with MS. The active ingredient is interferon beta 1a, which comes in a solution or powder, and is given by injection.

Cerebrospinal fluid (CSF)

CSF is a clear colourless bodily fluid found in the brain and spine. It is produced in the choroid plexus of the brain. It acts as a cushion or buffer for the brain's cortex, providing a basic mechanical and immunological protection to the brain inside the skull, and it serves a vital function in cerebral auto regulation of cerebral blood flow.

Citizens Information Board

The Citizens Information Board is the national agency responsible for supporting the provision of information, advice and advocacy on social services and for the provision of the Money Advice and Budgeting Service.

Clinical trials

Clinical trials are prospective biomedical or behavioral research studies on human subjects that are designed to answer specific questions about biomedical or behavioral interventions (novel vaccines, drugs, treatments, functional foods, dietary supplements, devices or new ways of using known interventions), generating safety and efficacy data.

Clinical Director

The primary role of a Clinical Director within a Hospital or Hospital Group is to manage and plan how services within a hospital are delivered and contribute to the process of strategic planning, influencing and responding to organisational priorities. He/she is the leading clinician manager in the hospital.

Copaxone (Glatiramer Acetate)

is the brand name for glatiramer acetate injection. Copaxone is a mixture of four amino acids, the natural building blocks of proteins in the body. Copaxone is the first non-steroidal, non-interferon MS drug therapy available to people living with relapsing-remitting MS.

Corporate Pharmaceutical Unit

The HSE Corporate Pharmaceutical Unit promotes best practice across the organisation in relation to the use of drugs and medical devices. It is responsible for evaluating the many schemes that exist in relation to the provision of drugs and devices for PwMS.

Dail Sub-Committee on Health

This sub-committee has been set up to consider legislation and review estimates from the Department of Health.

Department of Health

The organisation that ensures that Government policies are translated into actions and implemented effectively. The Department of Health is responsible for shaping the direction of the health system, protecting and improving the health and well-being of citizens and providing leadership in its delivery. It supports the Minister and Ministers of State in their implementation of government policy and in discharging their governmental, parliamentary and departmental duties.

Disease-modifying treatments

Disease-modifying treatments can affect the course of MS. Although not a cure, disease-modifying treatments act to reduce the number and severity of MS relapses. They also reduce the number of new MS lesions. It is not yet known whether these drugs will slow down the rate of disability in the long-term.

Glossary

European Medicines Agency (EMA)

The EMA is a European Union agency for the evaluation of medicinal products.

European Multiple Sclerosis Platform (EMSP)

EMSP is the umbrella organisation for 39 MS societies from 34 European countries. EMSP represents their interests at the European level and works to achieve its goals of high quality equitable treatment and support for persons with multiple sclerosis throughout Europe.

European Public Health Association (EUPHA)

The European Public Health Association is an umbrella organisation for public health associations and institutes in Europe.

Fampyra (prolonged release fampridine tablets)
- Fampyra is a slow-release oral tablet for the symptomatic treatment of walking impairment in adults with multiple sclerosis.

First-line therapy (sometimes called induction therapy, primary therapy, or front-line therapy)

First-line therapy is the first treatment that will be tried. Its priority over other options is usually either formally recommended on the basis of clinical trial evidence for its best-available combination of efficacy, safety, and tolerability or chosen based on the clinical experience of the physician.

Food and Drug Administration (FDA)

The FDA is an agency within the U.S. Department of Health and Human Services. The FDA is responsible for protecting the public health by assuring the safety, effectiveness, quality, and security of human and veterinary drugs, vaccines and other biological products, and medical devices.

General Practitioner (GP)

A general practitioner is a medical doctor who treats acute and chronic illnesses and provides preventive care and health education to PwMS.

Gilenya (Fingolimod)

Gilenya is a new type of therapy that can be taken orally rather than by injection or infusion. It is a disease modifying therapy (DMT) and targets the immune system to reduce relapses.

GP Visit Card

Certain people in Ireland who do not qualify for a medical card may apply to the Health Service Executive for a GP Visit Card. GP Visit Cards allow individuals and families who qualify, to visit their General Practitioner for free. All GP claims are processed and paid by the PCRS.

Health Products Regulatory Agency (HPRA)

HPRA's role is to protect and enhance public and animal health by regulating medicines, medical devices and other health products. It is also our role to monitor the safety of cosmetics.

Health Services Executive (HSE)

The HSE is the organisation that is responsible for providing health and social services to everyone living in Ireland.

High Tech Drugs Scheme

The High Tech Drugs Scheme allows for the supply and dispensing of High Tech medicines through Community Pharmacies. Such medicines are generally only prescribed or initiated in hospital. The medicines are purchased by the Health Service Executive and supplied through Community Pharmacies for which pharmacists are paid a PwMS care fee: the cost of the medicines and PwMS care fees are paid by the PCRS.

Hospital Pharmacists

Hospital pharmacists are healthcare professionals who practice in pharmacy, the field of health sciences focusing on safe and effective medication use. Hospital pharmacists instruct and counsel on the proper use and adverse effects of medically prescribed drugs and medicines.

Glossary

HSE Drugs Approval Group

The HSE Drugs Approval Group approves the funding stream for each newly approved drug and signs off on the NCPE's approval protocol.

HSE Map Centre

The HSE Map Centre allows users to search for their Local Health Office within their local HSE area.

Immune system

The immune system is a system of biological structures and processes within an organism that protects against disease.

Interferon beta (also interferon beta)

Interferon beta is a cytokine in the interferon family used to treat multiple sclerosis (MS). Interferons are not a cure for MS (there is no cure); the claim is that interferons may slow the progress of the disease if started early and continued for the duration of the disease.

Interferons (IFNs)

Interferons are proteins made and released by host cells in response to the presence of pathogens, such as viruses, bacteria, parasites, or tumour cells.

Intravenous therapy (IV therapy or iv therapy in short)

IV is the infusion of liquid substances directly into a vein.

Irish Pharmaceutical Healthcare Association (IPHA)

The IPHA represents the international research based pharmaceutical industry in Ireland.

JC virus or John Cunningham virus (JCV)

The JC virus is a type of human polyomavirus. The virus causes PML and other diseases only in cases of immunodeficiency, during treatment with drugs intended to induce a state of immunosuppression.

Judicial review

Judicial review is a way for the High Court to supervise the lower courts, tribunals and other administrative bodies to ensure that they make their decisions properly and in accordance with the law.

Lemtrada (alemtuzumab)

Lemtrada is an experimental drug treatment (an annual infusion) that is currently being tested in clinical trials for people with relapsing remitting MS. The new marketing name for Alemtuzumab is Lemtrada.

Local Health Office

A Local Health Office is the entry point to community health and personal social services. The wide range of services that are provided through Local Health Offices and from Health Centres include general practitioner services, public health nursing, child health services, community welfare, chiropody, ophthalmic, speech therapy, social work, addiction counseling and treatment, physiotherapy, occupational therapy, psychiatric services and home help.

Long-Term Illness Book

A Long-Term Illness book lists the drugs and medicines for the treatment of your condition, which will be provided to you free of charge through your pharmacist. You do not have to pay a prescription charge for drugs covered by your long-term illness book. Other drugs and medicines not related to the specified condition must be paid for in the normal way.

Long Term Illness Scheme

On approval by the Health Service Executive persons who suffer from one or more of a schedule of illnesses are entitled to obtain, without charge, irrespective of income, necessary drugs/medicines and/or appliances under the LTI Scheme. All LTI claims are processed and paid by the PCRS.

Glossary

Medical Card Scheme

The Medical Card Scheme allows recipients to receive certain health services free of charge. Eligibility is based on your means as to qualify your weekly income must be below a certain figure for your family size. Cash income, savings; investments and property (except for your own home) are taken into account in the means test.

Medical Records

Medical Records are the systematic documentation of a single PwMS's medical history and care across time within one particular health care provider's jurisdiction.

Minister of Health

The Minister of Health is the senior minister at the Department of Health in the Government of Ireland and is responsible for healthcare in the Republic of Ireland and related services.

Mitoxantrone

Mitoxantrone is an anthracenedione antineoplastic agent. Mitoxantrone is used to treat secondary progressive MS. Mitoxantrone does not cure multiple sclerosis, but is effective in slowing the progression of secondary progressive MS and extending the time between relapses in relapsing-remitting MS and progressive relapsing MS

MRI (Magnetic resonance imaging)

An MRI is a medical imaging technique used in radiology to investigate the anatomy and physiology of the body in both health and disease. MRI scanners use strong magnetic fields and radio waves to form images of the body.

MS Care Centre

The MS Care Centre is Ireland's only dedicated respite and therapy centre for people with Multiple Sclerosis. It offers short-term respite care, therapeutic services, neurological assessments and many social activities in a homely environment in the suburbs of Dublin.

MS International Federation (MSIF)

The MS International Federation is a unique global network of MS organisations. MSIF has 44 member organisations from around the world, and links to many others. Together we lead the fight against MS and work to improve the quality of life of people affected by MS in more than 90 countries.

MS Nurse

MS specialist nurses, also called MS nurses, provide specialist clinical advice and support to people with multiple sclerosis. They are usually the main point of contact for a person with MS and they often act to co-ordinate services, referring someone on to a doctor, or a therapist, or other appropriate services.

Multiple Sclerosis Ireland

MS Ireland is the only national organisation providing information, support and advocacy services to the MS community. MS Ireland works with people with MS, their families and carers, health professionals, students and other interested in or concerned about MS.

Multiple Sclerosis (MS)

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body.

Myelin sheath

The myelin sheath is a greatly extended and modified plasma membrane wrapped around the nerve axon in a spiral fashion.

Myelogram

A myelogram uses X-rays and a special dye called contrast material to make pictures of the bones and the fluid-filled space (subarachnoid space) between the bones in your spine (spinal canal).

National Centre for Pharmacoeconomics Ireland

The NCPE facilitates healthcare decisions on the reimbursement of technologies, by applying clinical and scientific evidence in a systematic framework, in order to maximise population wellness.

Glossary

Neurologist

A doctor who specializes in neurology is called a neurologist. A neurologist treats disorders that affect the brain, spinal cord, and nerves.

Occupational Therapy

Occupational Therapy helps people to do the everyday things that they want to do and need to do when faced with illness, injury, disability or challenging life events.

Ombudsman

The Ombudsman examines complaints from people who feel they have been unfairly treated by certain public bodies, for example, government departments, local authorities, the HSE. It provides a free public service that is open and accountable. The Ombudsman's job is to examine complaints in a fair and impartial way.

Optic Nerve

The optic nerve, also known as cranial nerve II, is a paired nerve that transmits visual information from the retina to the brain.

PwMS for PwMS Safety (PFPS)

PFPS is a World Health Organisation (WHO) initiative aimed at improving PwMS safety in health care. Networks of PFPS have been set up in a number of countries around the world. The purpose of setting up a network of PFPS is to promote understanding and dialogue around PwMS safety and the role PwMSs can play in developing new tools useful in PwMS safety.

Personal Public Service Number (PPS Number)

A PPSN is a unique reference number that helps you access social welfare benefits, public services and information in Ireland.

Pharmacists

Pharmacists are healthcare professionals who practice in pharmacy, the field of health sciences focusing on safe and effective medication use. Pharmacists instruct and counsel on the proper use

and adverse effects of medically prescribed drugs and medicines.

Physical Therapists (PTs)

Physical therapists are highly-educated, licensed health care professionals who can help PwMSs reduce pain and improve or restore mobility - in many cases without expensive surgery and often reducing the need for long-term use of prescription medications and their side effects.

Physiotherapy

Physiotherapy helps restore movement and function when someone is affected by injury, illness or disability.

Primary Care Reimbursement Service (PCRS)

The PCRS is part of the HSE, and is responsible for making payments to healthcare professionals, like doctors, dentists and pharmacists, for the free or reduced costs services they provide to the public.

Primary-Progressive MS (PPMS)

PPMS is characterized by steadily worsening neurologic function from the beginning. Although the rate of progression may vary over time with occasional plateaus and temporary, minor improvements, there are no distinct relapses or remissions.

Private Health Insurance (PHI)

Private Health Insurance is insurance against the risk of incurring medical expenses among individuals provided by entities other than the government.

Progressive multifocal leukoencephalopathy (PML)

PML is a rare and usually fatal viral disease characterized by progressive damage or inflammation of the white matter of the brain at multiple locations. It is caused by the JC virus, which is normally present and kept under control by the immune system.

Glossary

Progressive-Relapsing MS (PRMS)

PRMS the least common of the four disease courses is characterized by steadily progressing disease from the beginning and occasional exacerbations along the way. People with this form of MS may or may not experience some recovery following these attacks; the disease continues to progress without remissions.

Quality and PwMS Safety Directorate

The Quality and PwMS Safety Directorate monitors and implements quality and PwMS safety reviews throughout HSE service provision. Quality and PwMS safety goals are delivered by a combination of strong management and clinical leadership with clear accountability for quality in the service delivery.

Rebif (Beta-Interferon 1a)

Rebif belongs to a class of medicines known as interferons. These are natural substances that transmit messages between cells. Rebif is a highly purified soluble protein, which is similar to the natural interferon beta that is produced in the human body. It has been shown to reduce the number and the severity of relapses and to slow the progression of disability in people with MS.

Relapsing-Remitting Multiple Sclerosis (RRMS)

The most common disease course of MS is characterized by clearly defined attacks of worsening neurologic function. These attacks - also called relapses, flare-ups or exacerbations - are followed by partial or complete recovery periods (remissions), during which symptoms improve partially or completely and there is no apparent progression of disease.

Remission

Remission is the state of absence of disease activity in PwMS known to have a chronic illness that cannot be cured.

Secretary General of the Department of Health

The Secretary General of the Department of Health is responsible for administrative management of the Department of Health. The Secretary General is the highest-ranking member of the Department of Health, managing daily operations and reporting directly to the Minister for Health.

Second-line therapy

Treatment that is given when initial therapy (first-line therapy) doesn't work, or stops working.

Secondary-progressive MS (SPMS)

SPMS follows after the relapsing-remitting course. Most people who are initially diagnosed with RRMS will eventually transition to SPMS, which means that the disease will begin to progress more steadily (although not necessarily more quickly), with or without relapses.

Subcutaneous Injection

An injection given in the fatty layer of tissue just under the skin. These injections are given because there is little blood flow to fatty tissue, and the injected medication is generally absorbed more slowly.

Surgery Session

The majority of TD's have times when they are available at different places within their constituency for constituents to meet and discuss problems with them. These sessions are often called surgeries and details are usually advertised in local papers and in such places as public libraries.

Symptom management

Care given to improve the quality of life of PwMS who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of a disease, side effects caused by the treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, palliative care, and supportive care.

Glossary

Teachta Dála (TD)

A TD is a member of Dáil Éireann, the lower house of the Oireachtas (the Irish Parliament).

Tecifidera (dimethyl fumarate or DMF)

Tecifidera is a drug for treating relapsing-remitting multiple sclerosis (RRMS).

Tysabri (Natalizumab)

Tysabri is given to PwMS with highly active forms of relapsing-remitting MS or those who have failed on other disease-modifying therapies. 'Highly active' is defined as two or more disabling relapses in a year and the presence of more lesions on the brain in an MRI scan.

The Oireachtas (Oireachtas Éireann)

The Oireachtas is the legislature of Ireland. The Oireachtas consists of:

- The President of Ireland
- The two Houses of the Oireachtas
- Dáil Éireann (Lower house)
- Seanad Éireann (Upper house)

Vertigo

Vertigo is a subtype of dizziness in which a person inappropriately experiences the perception of motion (usually a spinning motion) due to dysfunction of the vestibular system

'Your Service, Your Say'

The HSE 'Your Service, Your Say' policy is provided for in Irish law and ensures that everyone has a right to make comments about the services they have received. The HSE welcome all comments, compliments and complaints from service users, carers, visitors and the community about the services it provides.

Acknowledgments

The development of this Handbook was supported by an unrestricted grant by Genzyme Ireland.



MS Information Line

The MS Information Line is there to provide professional and confidential support when it's needed. You are not alone - please get in touch if you need to talk about your MS.

Why call the MS Information Line?

- Are you newly diagnosed with MS and feeling worried, frightened or simply looking for more information?
- Have you been living with MS for some time and are experiencing difficulty with aspects of it?
- Does a member of your family, a colleague, a neighbour or a friend have MS and you would like some support information?
- Would you just like a friendly listening ear?

What can we do?

- We provide information on a wide range of topics related to MS including potential treatment options, symptom management and the different ways that MS can affect people's lives
- We help people source information about benefits and entitlements, statutory services, employment issues, insurance and many other areas
- We provide general and up-to-date information about MS to health professionals and students
- We make referrals to our nationwide team of Regional Community Workers and voluntary Branch network

Monday - Friday, 10am-2pm

 **Call: 1850 233 233**

 **Email: info@ms-society.ie**

GET SOCIAL

Join our incredibly active MS community online to stay informed, meet new people and share experiences!

Website: www.ms-society.ie

Read the latest news over on our blog; check out what's happening in your area on the events calendar; sign up to one of our national fundraisers or hold your own and find out all about how MS Ireland supports people with MS through services, advocacy and research.

eNews: Sign up at www.ms-society.ie

Our informative online monthly newsletter is sent straight to your inbox full of the very latest on MS Ireland activities and Irish and international MS developments including topical updates about potential new treatments, benefits and entitlements and important upcoming events.

Facebook: Multiple Sclerosis Ireland. www.facebook.com

As our most popular community network (with over 6,000 active members), this is where we post the latest news, ask our Tuesday Question which always gets people talking and encourage our supporters to share their achievements.

Twitter: @MSIreland. www.twitter.com

Sharing breaking news with our ever-growing number of MSers (that's over 3,000 so far) and talking to and sharing updates from our friends and colleagues in the international MS community is what you'll find here.

YouTube: MS Society of Ireland. www.youtube.com

This is where you can watch over 70 videos ranging from conference presentations from leading international health professionals to living with MS personal stories and fundraising campaign clips.

Can't seem to find us?

Don't worry! Simply open up a new web browser and either:

- 1 Go to www.ms-society.ie and click the Facebook, Twitter and YouTube icons or
- 2 Go to www.google.ie and type in 'Multiple Sclerosis Ireland' followed by either 'Facebook', 'Twitter' or 'YouTube' and we will appear as the first search result. Click and you're there!

