
MS Treatment Decisions



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.

CONTACT

Monday - Friday 10am-2pm



Call: 1850 233 233



Email: info@ms-society.ie

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 or 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

GET SOCIAL

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](https://www.facebook.com/MultipleSclerosisIreland)



As our most popular community network 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](https://twitter.com/MSIreland)



Sharing breaking news with our ever-growing number of MSers, talking to and sharing updates from our friends and colleagues in the international MS community.

YouTube: [MS Society of Ireland](https://www.youtube.com/channel/UCqWz8v8v8v8v8v8v8v8v8v8)



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!

MS Treatment Decisions

Introduction

This guide aims to help people with Multiple Sclerosis (MS) to access the highest possible standards of care from clinicians, in accordance with international recommendations about best practice in treatment of MS.

This guide is aimed at:

- People with a diagnosis of MS or Clinically Isolated Syndrome (CIS)
- People who have suspected MS and are awaiting formal diagnosis

This guide recommends that:

- People with MS and their clinicians establish a plan for regular monitoring of disease activity to see whether treatment is working
- People with MS have access to high quality information about the various treatment options available, so as to be able to make informed decisions
- People with MS and their clinicians engage in shared decision-making regarding treating and monitoring MS
- People with suspected MS should be able to access an urgent referral to a neurologist and prompt diagnosis
- People with relapsing forms of MS should be able to access early treatment with a disease-modifying therapy (DMT) when appropriate

This guide aims to empower and equip people with MS or suspected MS to:

- Understand the importance of early diagnosis and early treatment (if appropriate)

- Explain to healthcare professionals what is most important to them and what their treatment goals are
- Ask questions until they feel they have all the information they need to make informed decisions regarding their treatment and care
- Understand the importance of regular MRI scanning to monitor disease activity, and be able to discuss scan results and their implications with healthcare professionals
- Be able to monitor their MS by keeping records of symptoms and other factors that impact on health and wellbeing, such as side effects from treatments
- Be confident when engaging in discussions with healthcare professionals about treatment options, so the decision-making can be shared
- Understand that disease activity may be ongoing, even when they are feeling well.

This guide recommends that people with MS have access to a certain standard of treatment and care. However, due to resource restrictions in Ireland, some people experience difficulties accessing the services they need. MS Ireland continually advocates for greater investment in neurology services so that people with MS and other neurological conditions can receive the best possible treatment and care. This guide also contains suggestions for how people with MS can advocate for improvements in services.

The importance of early diagnosis and early treatment

For most people, the first point of call when experiencing suspected MS symptoms is their family doctor or GP. Once MS is suspected, an urgent referral needs to be made to a neurologist – preferably a neurologist with a specialist interest in MS, as these doctors will have broad experience of the long-term management of MS and an in-depth

knowledge of the latest diagnostic criteria, treatment options and monitoring processes. MS specialist nurses also play a key role in providing practical and emotional support post-diagnosis and in supporting people with MS with the ongoing management of their illness. MS Nurses are seen as a highly valuable source of information and support by people with MS (De Broe et al., 2001; While et al., 2009; Colhoun et al., 2015).

Thanks to developments in MRI scanning and improved understanding of the disease mechanisms in MS, it is now possible to diagnose MS at least 10 times more quickly than would have been possible in the early 1980s (Marrie et al, 2005). In about one in five cases, this can happen after an MRI scan following a single relapse event (Runia et al., 2013), but often more than one MRI scan will be needed over a period of time to confirm the diagnosis. Where a diagnosis is not received straight away, the person with suspected MS should stay in regular contact with their neurologist and their team for ongoing monitoring and repeat MRIs. A prompt diagnosis means that people with MS and their healthcare professionals can start to treat and manage the disease as early as possible.

What can you do?

- If your GP or another healthcare professional has told you that they suspect MS, ask for an urgent referral to a neurologist, preferably one with a specialist interest in MS
- Request early access to diagnostic procedures, including an MRI scan
- Stay in touch with your MS team for ongoing monitoring if you do not receive a diagnosis straight away
- If there is a history of MS or other neurological conditions in your family history try to provide the GP with as much information as possible

Early treatment with a DMT can reduce disease activity and improve long-term outcomes

Recent research now strongly suggests that long-term outcomes for people with relapsing forms of MS are improved by early identification, early treatment with disease modifying therapies (DMTs) and regular monitoring (Dobson et al, 2014, Goodin et al, 2012a; Goodin et al, 2012b; Cohen et al, 2012; Butzkueven et al, 2014; Cocco et al, 2014; among others).

At present, there are no licensed treatments for primary progressive MS and most licensed DMTs are not indicated for secondary progressive MS. Therefore treatment options for people with progressive forms of MS remain limited at present, although there have been some promising recent clinical trial results for medications for progressive MS.

What can you do?

- Ask your healthcare professionals whether it is appropriate to start treatment with a DMT and find out which options are available
- Be prepared to ask difficult questions of your healthcare professionals about the potential long-term risks of non-treatment – it is important to be aware of these potential risks in order to make a fully informed decision about if and when to start treatment
- While you are making a decision about if and when to start treatment, consider addressing lifestyle factors that may impact on the course of MS – for example, stopping smoking and starting regular exercise

Which DMT?

Different DMTs work in different ways and each is associated with a particular set of benefits and possible side effects. DMTs also vary in how they are administered and how often they are taken.

There are various factors that your neurologist may consider in deciding which DMT to prescribe, including how active your MS is, the risk of adverse reactions versus long-term benefits, other relevant medical history that may impact on the safety and efficacy of particular medications and your own preferences and treatment goals. This is where the value of shared decision-making comes into play.

Shared decision-making – play a key role in decisions about your treatment

People with MS should play an important role in deciding if and when to start treatment, which DMT to take and whether to change treatment following ongoing monitoring. Everyone will have different treatment goals depending on their values and lifestyle and these should play a key part in discussions with healthcare professionals about what DMT to take. Although MS can be very unpredictable, healthcare professionals should be able to provide information on the likely disease course and potential benefits of a particular treatment option. This can be weighed up against the risks associated with taking particular DMTs which vary from minor side effects such as mild allergic reactions, to serious and rare effects such as Progressive Multifocal Leukoencephalopathy (PML).

How DMTs are administered should also be discussed – administration methods vary from oral tablets taken once or twice daily to infusions that can only be delivered in hospital. Others require the person with MS to inject themselves, varying from daily to once every two weeks. Again, the lifestyle and preferences of the person with MS and the relative convenience and comfort of the different administration methods and frequency should be factored in when considering possible treatment options.

Some lifestyle factors that may be considered in discussions between a person with MS and their healthcare professionals about treatment options include:

- Family life and family planning
- Employment and career planning
- Education and training
- Hobbies
- Holidays and travelling

Evidence suggests that when people with MS feel well informed and empowered to play a role in planning their treatment, and have a positive and trusting relationship with their healthcare team, they are more likely to comply with treatment and are therefore less likely to experience serious relapses (de Seze et al., 2012; Costello et al., 2008; Remington et al., 2013; Bunz et al., 2013).

What can you do?

- Work with your healthcare professionals to decide on the best treatment option for you. Explain what matters to you and ask questions until you feel well informed
- Prepare for appointments by making a list of questions and topics that you want to discuss. This may include symptoms, likely disease course, treatment options and the benefits and risks associated with different treatment possibilities

- Be informed about the side effect profiles of different medications and also possible long-term risks of delaying treatment or not taking a treatment – weighing these up against each other is an important part of making a fully informed decision
- Make a list of your lifestyle factors that will be important to you in making a decision about treatments. This may include family life, employment, careers and hobbies
- Find out how different treatments are administered and how often as these can be very important considerations in deciding on a course of treatment
- Look for other resources to help with these conversations. It can be helpful, for example, to talk to other people who have taken certain treatments (although remember that everybody is different and one person's experience with a medication may be very different to yours). Networking sites such as Shift.MS or your local MS Ireland Regional Office may be good sources of additional information. See the end of this booklet for a list of websites and contacts that may be helpful
- Continue to take any DMT that is prescribed
- If you decide not to start treatment or to discontinue treatment, make sure you have discussed this fully with your healthcare professionals and ensure that there is a monitoring plan in place

diary' that records symptoms, medication side effects and general health and wellbeing. There are now also a range of apps that can be used for this purpose.

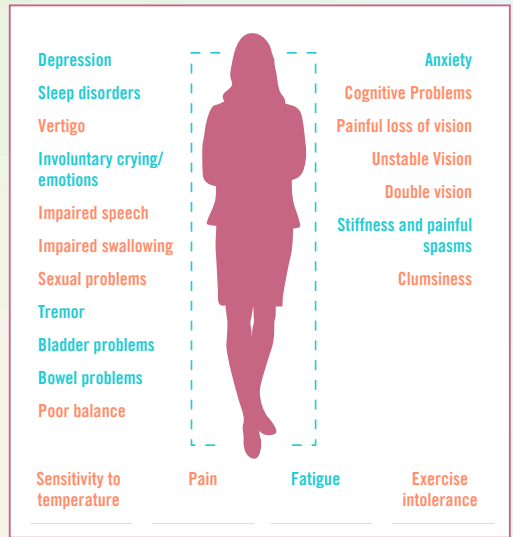


Figure 1: Take positive action to monitor these symptoms, especially the ones shown in blue, and keep an MS diary to discuss at appointments with healthcare professionals (Compston et al., 2008; Giovannoni et al., 2012). Original diagram taken and adapted from Giovannoni et al., 2015, *Brain health: Time matters in multiple sclerosis*.

Regular monitoring should be central to managing MS

Monitoring MS to see whether treatment is working is crucial to managing the disease and trying to ensure the best possible long-term outcomes. Your healthcare professionals should discuss a monitoring plan with you. This should include ongoing MRI scans – at least once a year if you are taking a DMT, and more often if MS is particularly active – and people with MS can also play a key role by keeping an ‘MS

All MS disease activity damages tissue in the brain and spinal cord even if this doesn't immediately lead to relapse. There is evidence that lesions (acute areas of damage) and brain tissue loss predict relapses and disability progression (Giovannoni et al., 2015). MRI brain scans should therefore be used to look for new lesions.

Regular monitoring of disease activity can give early warning that MS is not responding well to treatment. Timing is crucial, and clinical or MRI evidence that disease activity is poorly controlled should lead to discussion about the possibility of switching to a DMT that acts on the body in a different way.

What can you do?

- Keep an MS diary so as to have a record of symptoms, side effects and any other relevant information about your health and wellbeing so you can discuss this with your healthcare professionals at appointments. You can also use this to jot down any questions or thoughts that pop into your head in between appointments. See page 11 for an example of an MS diary
- Discuss strategies for managing your MS such as taking a DMT, symptomatic treatments, exercise and brain health
- Be aware of and be prepared to address lifestyle factors that may impact on MS and brain health, such as smoking, weight, exercise and alcohol consumption
- Understand relapses – know how to identify a relapse and what to do. Your MS Nurse is an important source of information and advice on what a relapse is and how to identify it and they should also be your first point of contact if you suspect a relapse. See pages 12 and 13 for further information on relapses
- Ask your healthcare team how they plan to monitor your MS and how often you will be having MRI scans
- Ask any questions you need to until you feel confident that you fully understand the results of your clinical assessments and MRI scans
- Ask whether it is appropriate to switch to another DMT if your MS is not responding well to treatment or if you are experiencing unpleasant side effects

Factors affecting access to treatments and medications in Ireland

As this guide makes clear, early diagnosis and early treatment with a DMT and ongoing monitoring of disease activity are crucial to managing MS and to giving people with MS the best possible chance of staying well into the future. However, due to resource limitations in Ireland, people with MS cannot always access healthcare services when they need them. There are currently critical shortages in staffing in neurology centres and lengthy waiting times for MRI scanning – no neurology centres have MRI access for routine referrals in under two months and seven of the eleven neurology centres cannot get access within one year of referral. Ireland also has less than half of the recommended number of MS Nurses for our population (Neurological Alliance of Ireland, 2016).

What can you do?

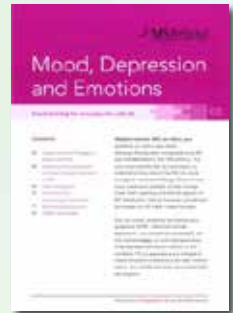
- Write to your local TD to express concern about the lack of resources for neurology services in Ireland. You can use the 'Lobby Your Local TD' section of the MS Ireland website: www.ms-society.ie/pages/email-your-td/lobby-your-local-td
- MS Ireland is always looking for people who are prepared to share their stories, to highlight the difficulties in accessing neurology services. If you have experienced difficulties accessing the treatment and care you need and are prepared to share your story with the media, please contact communications@ms-society.ie.

Further reading



MS Ireland's 'Access to Medicines Campaign Handbook' aims to enable people with multiple sclerosis to access the medicines they need to treat their condition and impact debilitating symptoms including impaired mobility,

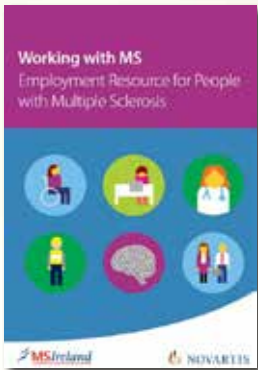
severe fatigue and cognitive difficulties. It provides practical advice for people with MS on their medical rights and options as well as how to engage with the health system.



MS Ireland's series of booklets on MS symptoms give advice on managing and monitoring various symptoms of MS.

All of the above publications are available in the 'Publications' section of the MS Ireland website:

www.ms-society.ie/pages/living-with-ms/information-centre/our-publications



'Working with MS – Employment Resource for People with Multiple Sclerosis' is an information and self-advocacy resource for people with MS, on their employment rights and options.

MS Ireland has detailed information sheets on each of the DMTs that are currently available in Ireland here:

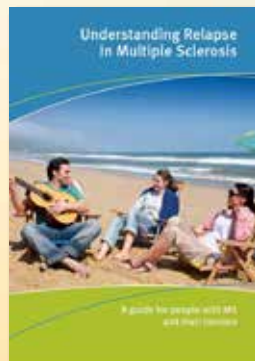
www.ms-society.ie/pages/living-with-ms/treating-&-managing-ms/disease-modifying-therapies

Contact MS Ireland's national office or your local regional office for printed copies.



'MS Explained' is a booklet aimed at those newly diagnosed, explaining what MS is, how you may experience it, treatments, interventions, aspects of living with MS and sources of

support available.



'Understanding Relapse in Multiple Sclerosis – A guide for people with MS and their families' can be downloaded here. This booklet contains information on how to identify a relapse and what to do if you suspect a relapse

www.ms-society.ie/pages/living-with-ms/treating-&-managing-ms/relapses

Apps

The following is a useful list of apps to help you to monitor and manage your MS:

<http://www.healthline.com/health/multiple-sclerosis/top-iphone-android-apps#2>

health products once they are available on the market and responds quickly to any safety or quality concerns. Medication side effects can be reported directly to the HPRA as well as to healthcare professionals.

www.hpra.ie

Sources of further information

MS Ireland's Information Line provides professional and confidential support to everyone living with multiple sclerosis. The Information Line is open 10am to 2pm Monday to Friday.

Call **1850 233 233** or
email info@ms-society.ie

MS Ireland provides a range of services and activities at a local level to people with MS, their families, health professionals and others interested in or concerned about MS. Locally our services are provided by professionally trained staff in our ten MS regional offices and a dedicated team of volunteers at our 38 voluntary Branches. You can find contact details for services in your area at:

<http://ms-society.ie/pages/community/services/local>

Shift.MS is a social networking site for people with MS. You can connect with other people with MS and talk about issues that matter to you:

www.shift.ms

The Health Products Regulatory Authority (HPRA) grants licenses to companies to make, distribute and market medicines in Ireland after a review of their safety, quality and effectiveness. The HPRA continuously monitors medicines, medical devices and other

Other useful websites:

Health Service Executive

<http://www.hse.ie/eng/>

HSE National Healthcare Charter

<http://www.hse.ie/eng/services/yourhealthservice/hcharter/Charter.html>

HSE Patient Safety – It's Safer to Ask

<http://www.hse.ie/eng/services/yourhealthservice/focus/ask.html>

Overview of health services for people with disabilities

http://www.citizensinformation.ie/en/health/health_services/health_services_for_people_with_disabilities/

Neurological Alliance of Ireland

<http://www.nai.ie/>

Mental Health Ireland

<http://www.mentalhealthireland.ie/>

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Acknowledgements

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Example of MS Diary

Taken from - <https://www.mstrust.org.uk/a-z/diary-symptoms>

Date: / /

Note:

Mon Tue Wed Thu Fri Sat Sun

Friday 7 May

Yesterday I was so tired and achy I didn't know what to do with myself. Dinner was easy, just to shove something in the oven for 20 mins. I was so far gone in fatigue-land it was like my sofa was keeping me prisoner. When I get tired like this, I have huge concentration difficulties and problems finding words - Does anyone else? Ask on MS people discussion list.

Saturday 5 June

This week fuzziness in my leg has moved up to my arm. Had some pains in my hand also one day, but it has been mostly ok. It mostly feels like both arm and leg is slightly "weaker" and fizzy compared to the left side. Must remember to mention to Sally (MS nurse) on Tuesday.

Saturday 4 September

I've not slept very well for a few weeks now and it is getting worse and worse. At the moment my eyes are aching as if I rubbed soap into them, and my eyelids are heavy like they are made of lead. I guess some of this lack of sleep comes from worrying about getting the new kitchen put in but its making fatigue even worse!

UNDERSTANDING RELAPSE IN MS



RELAPSE

What is a Relapse?

- An episode of neurological dysfunction
- When your immune system attacks the brain
- New or returning worsening symptoms lasting more than 24 hours

Possible SYMPTOMS



Blurred Vision



Double Vision



Areas of numbness



Bladder/Bowel issues



Fatigue



Loss of Balance



Pins and needles



Cognitive issues



RELAPSES
CAN VARY IN
LENGTH AND
SEVERITY

NO TWO RELAPSES ARE THE SAME



30% of people with MS

DO NOT report relapses¹

If you have a Relapse, it may be a signal to start or change disease modifying therapy





When is a Relapse **NOT** a Relapse?

pseudo- relapse

When symptoms are caused by other factors:

- Tiredness
- Heat
- Stress
- Infection

WHAT TO DO IF YOU HAVE A RELAPSE

Tell your GP

- Agree on severity of relapse
- Exclude pseudo-relapse
- Agree on a course of action

Stay in contact!
IF IN DOUBT, SHOUT!



Tell your MS nurse/ consultant

"Steroids only shorten relapse, but DO NOT change trajectory"

A **Relapse** may be a signal to **start** or **change** disease modifying therapy



Goals of therapy in RRMS

- Reduce relapses
- Reduce MRI activity
- Preserve ability



Tips from MSers

- Record your relapses
- Avoid stress
- Keep an eye on steroid use
- Communicate honestly with your healthcare team
- Adhere to treatment
- If in doubt, shout!



With thanks to MS Ireland and participants in relapse forum

MS Treatment Decision Journey Map



This is Nora. She is a 26 year old travel enthusiast, who works in retail. Nora has very recently been diagnosed with Multiple Sclerosis.



Nora has a consultation with her neurologist. She understands that asking hard questions will help her to make a fully informed decision on her care plan going forward. She has a list of questions to ask her healthcare team, so that she gets all the information she needs. It has been recommended that Nora commence treatment with a D.M.T. Her healthcare team provide her with information on suitable treatment options.



Nora decides to explore her options. She reads the information provided by her healthcare team. She also carries out her own research from credible and reliable sources.

Are there things I can do to help improve my general brain health?

Would this treatment work for me and my life?

Maybe I should talk to someone who has taken this treatment.

What are my treatment goals?

What are the side effects and long-term effects?

How are these treatments administered, and how often?

Are there any changes I can make for a healthier lifestyle?

Perhaps I should make a list of questions and thoughts so I can discuss them with my doctor or MS nurse.

After exploring her options and considering the various factors influencing her decision, Nora discusses her treatment choices with her healthcare professional. She outlines the things that are most important to her in deciding a treatment option. She discusses her treatment goals. Nora makes a shared decision on treatment with her healthcare team.

... 6 months later



So far, Nora is responding well to treatment. She is aware that there can be disease activity, even when she is feeling well. She adheres to her treatment plan. Regular monitoring by her healthcare team, and Nora's own records of any issues she encounters help to achieve a positive outcome for Nora.



- MS Regional Office
- ★ MS National Office
- MS Voluntary Branches
- MS Care Centre

To make contact: Call: 01 678 1600
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www.ms-society.ie

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