

Working with MS

Employment Resource for People with Multiple Sclerosis



Will I be able to continue working?

Do I need to tell my employer about my diagnosis?

Will my employer be supportive?

How will MS affect my career progression?

What are my legal rights?

Introduction

Multiple Sclerosis is a neurological condition usually diagnosed between the ages of 20 and 40, at a critical phase for career development. If you have been diagnosed with MS (or Clinically Isolated Syndrome), you may have many questions about employment, such as:

- *Will I be able to continue working?*
- *Do I need to tell my employer about my diagnosis?*
- *Will my employer be supportive?*
- *How will MS affect my career progression?*
- *What are my legal rights in relation to employment?*
- *What obligations does my employer have towards me?*

Many people with MS continue to work full-time many years after their diagnosis. A recent survey of 594 people with MS in Ireland found that almost half of them were still in paid employment.

While some jobs or career paths may be more suitable than others, MS won't necessarily stop you pursuing any specific careers. Employers can support and enable an employee with MS to continue in their employment as a productive member of the workforce.

Because of the unpredictable nature of MS, however, it can often be difficult to determine if and when you will or should make changes to your employment commitment.

This booklet aims to provide some guidance so that people with MS can make informed decisions about their working life.



Many people with MS continue to work full-time many years after diagnosis

Employers can support and enable an employee with MS to continue as a productive member of the workforce

MS and Employment Law

Pursuant to the Employment Equality Acts 1998-2015, employers are not allowed to discriminate against an employee or a potential employee with a disability.¹ There are different categories of disability including physical disabilities, chronic medical conditions and long-term illnesses.²

Disclosure – should I tell my employer or potential employer that I have MS?

The decision of whether or not to disclose that you have MS to your employer or potential employer is a personal one. While legal protections are in place, discrimination still happens in the workplace and worry of discrimination is often the main reason people resolve to deal with their MS without seeking support from their employer.

It is up to you to decide whether or not you should tell your employer that you have MS. You have no legal obligation to disclose, except if your symptoms pose a potential health and safety risk to yourself or others. Situations where this may arise (depending on your symptoms) are if your job involves driving or operating heavy machinery, or if your MS prevents you from performing certain duties.³

There may be clear advantages to telling your employer about your MS. Your employer may

be able to provide certain supports to help you continue in your work. Attempting to hide your illness from your employer and colleagues may be an additional cause of stress and worry.

If you decide to tell your employer about your MS, you should gather as much information as possible to help them understand your condition. You can download the booklet 'MS Explained' from MS Ireland website: www.ms-society.ie

You might explain how MS impacts you and your work. Where possible, offer solutions to the difficulties you encounter – see the section on '**Reasonable accommodations**' for more information.

The same legislation also applies if you are looking for a new job. Therefore, if you interview for a job or apply for a promotion and you are the best candidate but you're turned down because you have MS, the employer (or potential employer) is breaking the law. In reality, of course, it can be difficult to prove that you didn't get the job because of your MS.

A lot of application forms now ask if you have a disability. This information is usually collected for monitoring purposes and should have no bearing on the application process. You are under no obligation to disclose that you have MS at this stage. In some cases,



Your employer may be able to provide certain supports to help you continue in your work

employers may ask if you have a disability so that they can make the application process as fair as possible. For example, if you have mobility issues they may want to ensure that the interview venue is accessible for you, or if the interview includes a written test, you may be able to avail of extra time to complete it if you think that might be helpful.

Like most discussions during an interview, if you decide to disclose your MS make sure you consider how you can do so in a positive way. For example, you could describe your resilience in overcoming some of the challenges MS has posed for you; this can show your determination, innovation and flexibility. After being selected for a job, some employers ask new employees to complete health surveys. These may ask quite specific questions relating to illness, and can appear to leave the employee with little choice but to disclose if they have a condition like MS. There is no obligation on a person with MS to disclose it to an employer or potential employer but being untruthful when asked about your health or lying in a questionnaire/survey may cause difficulties for an employee at a later stage. Remember, if you feel that you are left with no option but to disclose your MS, you will be protected by the law.

Ultimately, whether or not you disclose that you have MS, and when you do so, is a personal decision. You may have very legitimate concerns about how your employer will react but just remember that the law gives you clear protections and if you feel you have been discriminated against or treated unfairly there are steps you can take to remedy unfairness and wrongdoings. See the section below on '**What should I do if I feel I have been treated unfairly by an employer?**'

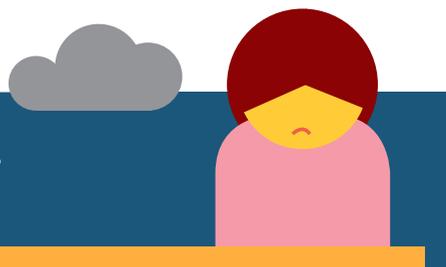
Reasonable accommodations

What are reasonable accommodations?

Employers are legally obliged to try to make reasonable accommodations for an employee with a disability. What a 'reasonable accommodation' is will depend on a number of factors including the size of the company, the nature of the work and how the disability or illness affects the individual. Employers are not expected to make adjustments where costs would be disproportionate and excessive.

Research has found that, for many people with MS, fatigue is the most common symptom associated with the decision to reduce working hours or leave employment.⁴

Attempting to hide your illness may be an additional stress and worry



Some examples of reasonable accommodations to help deal with fatigue include:

- Changes to work schedules to allow more regular breaks
- Allowing an employee to perform some or all of their work from home from time to time
- Allowing an employee to sit rather than stand in jobs that usually require standing for long periods, such as a cashier
- Offering a quiet place/location with a couch or chair to take rest during the day
- Varying work demands and activities



Other issues that people with MS might experience in the workplace include eyesight problems, continence problems, memory difficulties and loss of dexterity in the limbs. Some examples of reasonable accommodations for these problems include:

- Installation of hand rails in the toilet
- The use of voice recognition software for someone who finds typing difficult
- The use of reminders/alerts to help with remembering tasks and appointments
- Moving a desk so it is nearer to the toilet
- Allowing an employee to park closer to the building

Assistive technology can be hugely helpful for a person with MS in the workplace. For example, someone with eyesight problems might use screen-reading software, or someone who finds typing difficult due to stiffness or loss of manual dexterity can use voice recognition or speech-to-text software so that they can talk and the programme types for them.

If you are discussing your MS with your employer, it can be helpful for you to have already thought about what changes and adjustments might be beneficial for you. Think carefully about your job role and what aspects of it might present difficulties for you, and try to have some suggestions ready so that the discussion will be as positive and practical as possible.

In some cases, your employer may decide to arrange an occupational health assessment to see what accommodations will best suit your needs. There are various companies who provide this service and the assessor may not necessarily have an in-depth understanding of MS.

Employers are legally obliged to try to make reasonable accommodations for an employee with a disability

Grants and subsidies can be accessed by employers. For further information visit www.welfare.ie



If your employer informs you that they are seeking an occupational health assessment you should seek advice from the healthcare professionals who are supporting you. These could include your neurologist, GP, MS Nurse, occupational therapist or physiotherapist. They can help you describe your symptoms and how they affect you. Furthermore they can provide strategies on how to manage your symptoms in the workplace, so that you can present the assessor with accurate information.

Sick leave and sick pay

Entitlement to sick leave and sick pay are at the discretion of individual employers – there is no automatic right in law to be paid while off sick and having an illness like MS does not confer any additional rights in this regard. Every company should have its own policies and procedures pertaining to sick leave and sick pay. Most company policies allow for a certain number of discretionary sick days with the requirement for a medical certificate if you need to be off work for longer than 3 or 5 consecutive days, for example. If you are not entitled to sick pay from your employer, you may be able to apply for Illness Benefit if you have enough social insurance contributions.

Financial supports for employers

A lot of the reasonable accommodations described above can cost little to put in place. Where there is a cost involved, employers may get some financial support towards this.

Workplace Equipment Adaptation Grants can be accessed by employers in the private sector to meet the needs of employees with disabilities. A grant is available up to a maximum of €6,350⁵, and may be used towards the costs of adapting equipment or premises.

The Wage Subsidy Scheme offers financial

incentives for employers in the private sector to employ people with disabilities who work more than 20 hours per week. Where it is perceived that there is a productivity shortfall of 20% or more for a disabled employee in comparison to a non-disabled peer, the employer can apply for a subsidy of €5.30 per hour.⁶

You or your employer can contact your local Employment Services Office or Citizens Information Centre to enquire about these two schemes. Further information can also be found at www.welfare.ie

The Disability Awareness Training Support Scheme is a grant that employers can access to source disability awareness training for their staff. Contacts for the Disability Awareness Training Support Scheme can be found at www.welfare.ie

The Employee Retention Grant Scheme is designed to help employers in the private sector to retain an employee who has acquired an illness or disability that impacts on their ability to do their job. The grant facilitates employers to implement a retention strategy so that the employee can either remain in his/her current role or be re-trained so that they can take up employment in another department. Further information on this grant and contact details for the scheme can be found on www.welfare.ie⁷

How should I manage communications with my employer?

During negotiations with your employer, you can help yourself by being proactive in making sure you are aware of all relevant company policies and practices relating to attendance management and return to work.

This can help you to reach a clear agreement and understanding of what is expected of the employee and employer in scenarios such as sick leave, extended time off and attending appointments. You should keep any communications between yourself and your employer such as emails and letters, and also a record of the dates and times of any phone calls and what was discussed in them. In a lot of cases any potential conflict can be avoided through clear communication.

I feel I have been treated unfairly by an employer. What can I do?

If you feel that you have been treated unfairly by your employer because of your MS, your first step should be to ensure that all internal company processes have been followed. You will need to have spoken to the HR department, if there is one, and followed any complaints or grievance procedures.

If you have not been able to reach a satisfactory resolution internally, you may be able to seek assistance from the Irish Human Rights and Equality Commission (IHREC).⁸ The IHREC is generally responsible for promoting respect for equality and

human rights in Ireland and may represent a person bringing a claim for discrimination.⁹

The Workplace Relations Commission (WRC) is similar to a court and it can investigate and decide on equality cases. The first step is to lodge a complaint with the WRC, which must be done within six months of the last act of discrimination (e.g. a dismissal).⁹

The WRC may offer mediation to you and your employer. If a mutually satisfying conclusion is reached through mediation, both sides must sign a mediation agreement. If an agreement is not reached through mediation, an Adjudicating Officer is assigned to the case who will conduct an inquiry and consider submissions from both sides. At the end of their investigation, the Adjudicating Officer will give a decision which can be appealed by either party.

Further information, along with a complaint form, can be found at www.workplacerelations.ie

FLAC (Free Legal Advice Centres) can provide free consultations to determine whether you have a case and how you should go about pursuing it.



Changing direction

For some people with MS, making changes to their employment situation may be the right thing to do. There may be options for retraining or redeployment within your organisation, or you may decide to pursue further education or training in a different area altogether. **The National Learning Network, Employability and AHEAD** (Association of Higher Education Access and Disability) are organisations that may be able to help if you are considering a change of direction. The websites for these organisations are listed at the end of this document.

There are various financial supports that may be available for people who have been out of work due to illness or disability and are now considering returning to employment, education or training, including Partial Capacity Benefit and Back to Education Allowance. Your local Intreo Centre or Social Welfare office should be able to advise you about these and other payments.

Working Life

People share their experiences working with MS

My Working Life with MS

Naomi Donaldson



Did you tell your employer about your diagnosis? Why (not)? How did they react?

My sister also worked with us and she had been diagnosed with MS the year before I was. Work were very understanding so it was a no brainer for me to tell them.

What (if any) adjustments have had to be made in your working environment?

Small things like getting a new chair, footrest, moving desks to be nearer to the bathroom. And looking after myself.

My boss is so understanding if I'm not feeling 100% I can work from home, or not feel guilty about taking time off to get back to full health.

What type of employment do you have?

I'm a Customer Experience Specialist for RaboDirect, my job is mostly office based working with the operations and marketing teams, it also involves a small amount of travel.

I try to eat the healthy option in the canteen now... it's not always possible though... the lasagna and bangers & mash are hard to resist!

Were you working when you were first diagnosed with MS? What type of work were you doing? What else?

I was working for RaboDirect as Customer Care Team Lead, running the customer care center for the business. I managed a team of six staff dealing with customer queries and complaints. The job could be stressful at times and sometimes involved long hours.

I've also got a disabled parking permit as commuting was a nightmare between stress of buses being late or not turning up (I FREAK OUT, if I'm not in the office at least 15 minutes before I'm supposed to start work), the dreaded bladder control issues meant that an hour long bus journey was not possible and changes in temperature can bring on flare ups of MS



symptoms which could cause my legs to just go from under me without warning. Being able to drive right to the office door is such a relief.

How has MS affected your work life?

Thankfully it hasn't affected it too much. I've had more sick days than I would have had previously. When I ran the customer care center it was impossible to work from home, if there were serious issues I needed to be here. My new job gives me a lot more flexibility to work from home, or work different hours, instead of the rigid shifts in customer care.

What does the ability to work mean to you?

I think like everyone I have the "lotto" dream, I always say if I won the lotto I'd be straight out the office door, but actually being able to work is extremely important. My husband and I have a comfortable life, a nice home and there's always good food in the fridge. Working and having a steady salary allows me to treat my MS holistically... a healthy diet, holistic therapy treatments such as acupuncture and health supplements. I have fantastic health insurance through work, which also really helps.

But one of the most important things my job does for me is keeps me in touch with my friends and helps my sanity. I've worked for RaboDirect for almost 11 years, when I started here I was 24, I hadn't even met my husband.

I don't have time to let MS interfere in my life. I'm too busy living it!
If I am having a bad day, I always keep the proverb "This too shall pass" in mind

The support of your employer is extremely important

I've grown up here, I've made some of my best friends through work.

Being able to come into the office and simply say "I'm having an MS-ie day" and they understand that I'm not being lazy or ditz. This is part and parcel of the condition, and they accept that and reassure me that I can get through this. Having support in the workplace helps to reduce stress, which is essential for people with MS.

Anything else you feel is relevant

I know I've sung the praises of work and I know I am really lucky to have a job I love, but there's two main things that make this possible:

1. I am as stubborn as a mule. I don't have time to let MS interfere in my life. I'm too busy living it! If I am having a bad day, I always keep the medieval proverb "This too shall pass" in mind.
2. The support of your employer is extremely important. I am lucky to have an excellent health insurance package, a fantastic employee assistance program and most importantly a very understanding management team and colleagues. Employers need to understand that there can be an enormous amount of guilt associated with having MS, that you are making your colleagues' workload bigger, that you need more sick days than other colleagues, but it's not by choice.

My Working Life with MS

Paul McGovern



What type of employment do you have?

I work full time as a Civil Site Engineer for a main civil engineering contractor. It's an extremely fast paced role and comes with a lot of responsibility, i.e. completing works within a set timeline and always being within compliance of Health and Safety regulations.

Were you working when you were first diagnosed with MS? What type of work were you doing? What else?

At the time of diagnoses I was working on the Inchicore 12th Lock Green Route, ESB Ducting and Walkway, Grand Canal, Co. Dublin, this is the new walkway along the Grand Canal but is also a new power and fiber optic feed from Inchicore to Grange Castle for Microsoft, laid beneath walkway. My role on this was Civil Site Engineer.

Did you tell your employer about your diagnosis? Why (not)? How did they react?

I left work early to see my GP in the evening, then A&E the following morning. Thought would have been back at work day after I left early. This was the start of January. I got diagnosed after couple of days and work told me to take a month off with pay. I was able to begin to start taking in the shock of the whole thing. My employer was very supportive about it all. I couldn't have wished for any more from them, definitely can't fault them.

What (if any) adjustments have had to be made in your working environment?

The only adjustments I needed since being diagnosed is to be able to take a couple of days off a year for hospital appointments, i.e. Neurologist reviews, MRI's etc.

How has MS affected your work life?

MS makes you more tired than usual but somehow I find the energy for it. There's days I would be in the middle of a relapse and keep working. Sometimes I think I'm a robot, before and after work I feel dead but when at work, I'm able to do it. My line of work is 12hr+ days, five days a week.

What does the ability to work mean to you?

It's great to be still able to work, you keep your independence and self belief but I still wish for what all of us wish for, win the lotto and never have to work again.

Anything else you feel is relevant

Take life one day at a time, I found myself having to train my brain to



question itself, can I do it? Before I go and do it. That's become second nature to me now and I don't even notice I do it anymore. I work on construction sites so you're not walking around a nice hazard free flat area. I always study where I'm going, what's the danger? Can I avoid going

there? We make a million risk assessments in our minds everyday but the people with MS make just a few more than those that don't. When it comes to work, we all have the same goal, go home the way we arrived in, it's just a little bit more challenging for those with MS.

Take life one day at a time

It's great to be still able to work, you keep your independence

My Working Life with MS

Lucina Russell



I was working in my current job for over ten years when I was diagnosed with MS, five years ago. My work involving devising and running a range of arts and cultural events for different communities in Kildare, including school going children, youth groups, older people. I have commissioned films and pieces of sculpture. I also give grant aid and advice to arts groups in the county. There is quite a public aspect to my role, with lots of public speaking (and after 16 years, I still get nervous speaking in public!).

Did you tell your employer about your diagnosis? Why (not)? How did they react?

I became ill over a weekend at work and so my employer knew that I was unwell and was aware that I had been admitted to a neurological department. It became apparent that something dramatic had happened to me, so it was easier to be upfront about it. My line manager, work colleagues and



What type of employment do you have?

I work for a local authority (Kildare County Council) formulating cultural policy and I am employed as the County Arts Officer.

Were you working when you were first diagnosed with MS? What type of work were you doing? What else?

senior management were as shocked as I was with the diagnosis and were extremely supportive of me.

What (if any) adjustments have had to be made in your working environment?

A second work place, closer to home, was made available to me if and when I need it. Other than that, there have been few changes, as thankfully, my health is good.

How has MS affected your work life?

I have always been a hard grafter and I probably go above and beyond expectations to show how MS isn't affecting my work life. I try to balance my work according to how I am feeling, so for example, if I have a day where I have bad fatigue or nausea, I use it as an opportunity to catch up on more mundane, but necessary activities like deleting old emails. Occasionally, I may go into work a little late as fatigue can hit me in the morning time. But I always make up for the time later. I think that a certain level of stress is healthy and can keep the adrenaline going during big projects, but I try to avoid situations that will cause unnecessary stress.

What does the ability to work mean to you?

I am very lucky in that I love my job and my ability to work and support my family is very important to me. My work colleagues have been a great support to me.

I do worry about my ability to continue to work at the level and pace I do at the moment, but I need to balance those thoughts with my desire to embrace life and make the most of what I have now.

Anything else you feel is relevant

A diagnosis of a chronic illness is a terrible shock to the system. Having an employer that is sympathetic to my situation and who considered flexible working options has greatly helped me to continue in my job. In return, they have a dedicated and loyal employee.

One of the best pieces of advice that I got from my MS Society Regional Community Worker when I was first diagnosed with MS was not to make any drastic decisions about my employment, to take time and see what was possible.

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Sources of further information

Employer Disability Information Service

www.calledi.ie

Citizens Information

www.citizensinformation.ie/en/employment

Department of Social Protection

www.welfare.ie/en/Pages/Work-Supports-for-People-with-a-Disability_holder.aspx

Irish Congress of Trade Unions

www.ictu.ie

Irish Human Rights and Equality Commission

www.ihrec.ie

AHEAD (Association of Higher Education Access and Disability)

www.ahead.ie/graduate

FLAC (Free Legal Advice Centres)

www.flac.ie

The National Disability Authority has produced a guide for employers on retaining an employee who has acquired a disability:

<http://nda.ie/publications/employment/employment-publications/retaining-employees-who-acquire-a-disability-a-guide-for-employers.pdf>

National Learning Network

www.nln.ie

Employability

www.employability.ie

European Multiple Sclerosis Platform – Toolkit for Employers

www.emsp.org/news-messages/paving-the-path-to-participation-a-toolkit-for-employers/

References

1. Employment Equality Acts 1998-2015, s 6(2)(g)
2. Ibid s 2(1)
3. <http://www.irishstatutebook.ie/eli/2005/act/10/section/23/enacted/en/html>
4. <http://ijmsc.org/doi/abs/10.7224/1537-2073.2014-051>.
5. <http://www.welfare.ie/en/Pages/Workplace-Equipment-Adaptation-Grant.aspx>
6. http://www.welfare.ie/en/Pages/Wage-Subsidy-Scheme_holder_3176.aspx
7. <http://www.welfare.ie/en/Pages/Employee-Retention-Scheme.aspx>
8. <http://www.ihrec.ie/>
9. http://www.ihrec.ie/download/pdf/ihrec_employment_equality_rights_explained.pdf

About MS Ireland

Multiple Sclerosis Ireland is the only national organisation providing information, support and advocacy services to the MS community. We work with people with MS, their families and carers and a range of key stakeholders including health professionals, students and other interested in or concerned about MS to ensure that we meet our goals. MS Ireland is chiefly a services driven organisation, focused on providing timely, person-centered services that create independence and choice for person with MS and their family.

www.ms-society.ie

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