



Guide for **Employees**

Have you recently been diagnosed with Multiple Sclerosis (MS)?

You may be concerned about how you manage it in the workplace, and whether or not you should tell your employer.

As you know, MS is not the same for everyone. Symptoms vary and fluctuate over time, and sometimes within the same day. Some people have symptoms on a daily basis, others go weeks and months with no symptoms. This means there is no single answer or strategy that is right for everyone. However, MS is manageable and doesn't have to limit your financial goals or mark the end of your career.

The new generation of disease modifying therapies are not a cure for MS, but they can reduce how many relapses someone has and how serious they are. There are disease modifying therapies that minimise the number and severity of relapses, slowing down disease progression. These are important advances that can help you to remain in the workforce.

In this booklet we help you to consider the possible benefits and consequences of telling your employer, and review how MS can be managed in the workplace.



Telling your employer

For many people with MS, having a supportive employer is what enables them to remain employed. However, some employers have concerns about employing a person with MS, often because of misconceptions about how a person may be affected by this medical condition.

Whether you do, and how you choose to, tell your employer is up to you. It might depend on what you do, where you work and your relationship with your employer. You might choose to have an informal chat or you might make it a more formal meeting, possibly with the inclusion of a support person, perhaps from HR. You can also enlist support from the state MS organisations to help you prepare for the meeting.

If you tell your employer, you may want to write down what you discussed and send it to them afterwards. That way you have a record of when you first told them about your MS, as well as what was agreed. Remember, your employer is not allowed to tell your colleagues about your MS unless you have said it is ok for them to do so.

Many of us hold legitimate fears about 'coming out' because of the impact it will have on our work and friendships.

I feared it would affect my career advancement. However when I 'came out' I was overwhelmed by the support shown by my colleagues and fellow partners. I was also congratulated by clients. Another lawyer actually 'came out' to me admitting that she too has MS and a personal assistant also confided in me that she suffers clinical anxiety. It was so great not to feel alone and to be a sounding board for others suffering. I'm lucky to be in a workplace that encourages work life balance, that openly discusses mental illness and that has a dedicated human resource team that is passionate about stamping out inequality in our firm.

Catherine, 32 years old

Understanding the pros of ‘coming out’

Receive support: Your workplace is obligated to take your health into account and look at ways in which you can be accommodated. Depending on your type of MS and how the condition affects you, this could be as simple as starting your day later or moving the position of your desk. Telling your employer about your MS enables them to support you in these changes.

Debunk the myths: Telling people at work that you have MS creates opportunities to challenge the stigma around the disease. By opening up the communication channel and being honest about MS, you can raise awareness about the condition.

Share experiences: We are all human at the end of the day. Often as soon as you tell people you’re struggling, they’ll share with you their struggles. When you ‘come out’ people give you compassion and strength, and if you are having a bad day, someone to talk to.

Considering the cons of ‘coming out’

Experience stigma: Employers and colleagues may have negative views or inaccurate stereotypes about MS. They may also be concerned that you will be unreliable and frequently need to take time off, putting more pressure on them.

Challenge presumptions: Your employer may assume that you will not want or be eligible for further training or promotions. They might focus on your health status rather your talents and abilities.

Face fear: MS is not well understood. This is why it is important to debunk the myths. The old stereotypes of MS are no longer true and not everyone is aware of the medical advances that make this the case.

Managing MS in the workplace

If your MS is making it harder for you to do your job (whether for a period of time or permanently), there is support available. However, in order to access this support you need to tell your employer about your MS.

Discussing the possibility of making reasonable adjustments to your role is a good start to managing MS in the workplace. The official definition of 'reasonable adjustment' is 'a change to a work process, practice, procedure or environment that enables an employee with disability to perform their job in a way that minimises the impact of their disability'. Any adjustments will depend on the type of work you perform. For example, adjustments will be different for an office worker and a retail worker.

For example, you might ask for:

- More frequent breaks throughout the day
- A chair or stool (if your job requires you to stand)
- Flexible or reduced working hours, either temporarily (as you recover from a relapse), or permanently (if you prefer)
- Working from home on particular days of the week
- Moving your work station away from a heat source or closer to an air conditioning vent
- Reserving a parking space close to the entrance of your work.

I was admitted into hospital with a severe relapse and I was diagnosed with MS that same week.

I told my employer straight away: I was completely paralysed down my right side so I was going to be off for a while. I ended up being off for 4 months and when I returned I had a discussion with my employer about the reasonable adjustments we could put in place to enable me to continue at work. We agreed I would reduce my hours to 16 a week for a period of time while I recovered. It meant I was really productive when at work, and enabled me to take naps in the afternoon. I really appreciate my employer understanding and working around my MS.

Sommer, 35 years old

Having MS may mean that you need to take time off work (although this is not the case for everyone). If you have medical appointments to attend then you may ask to work around this time off as one of your reasonable adjustments. Check if your employer has a disability leave policy as time off for appointments may be included in this policy.

Returning to work after a break

If you have been off for four weeks or more (four weeks is the period of time that classifies sick leave as being for a long-term sickness) then you may find it helps to return to work gradually. It is also a good idea to arrange a meeting with your manager to discuss potential reasonable adjustments.



PERSONAL STORY

The benefit of starting my career in such a large company was the many and varied opportunities available. There were always new jobs to apply for and training courses to attend. If you worked hard and displayed initiative, there was a clear path ahead. And as always, I loved having a plan. As I began getting into the rhythm of working, my university life rolled out like a distant memory behind me. My career was pushing ahead and mind was racing with all that lay before me. Then I was diagnosed with MS out of nowhere and the pace of my life instantly changed.



However despite the relapses I experienced over the years, I continued to embrace new opportunities and roles at work. With time though MS definitely began making parts of my job difficult. Having legs that were becoming increasingly weak and unreliable meant standing up at the front of a room for a day's training was taxing. I was always anxious that increased pressure at work might cause a relapse, and worried that having time off would reflect poorly on my work ethic.

After a severe relapse I would learn that life on the outside never stops turning even when your own life stops in its tracks. After I returned to work a few months after a relapse, my manager had moved on and my training role no longer existed. Still, my organisation's support was incredible. They were incredibly loyal and sensitive to my situation. They put together a generous return to work schedule and although my role changed, at least I could go back into the office for a couple of hours at a time which was a huge relief.

Teisha, 41 years old

Taking control of your career

Even with reasonable adjustments in place, you may no longer be able or want to continue in your current job. This doesn't mean you have to give up working. There are a number of different options to explore before reaching that decision.

Moving to another position within the same organisation: It will depend on the organisation you work for, but there may be an option to move to another position that suits you.

Retraining: A diagnosis of MS is a life-changing event. It often prompts people to rethink their priorities and aspirations. It might make you re-think what you want to spend your time doing, and open the door to pursuing what you have always wanted to rather than what you had to do. This might include going back to study, or turning a passion into a small business.

Becoming self-employed: Going solo doesn't come without risks, but depending on your skills and expertise it may give you more flexibility to pursue your career aspirations and plan your work around your health.

My employer gave me full paid leave after my diagnosis and told me to take as much time as I needed. I took a week and a half off because I was keen for things to return to normal. My first week back at work was probably one of the worst experiences of my life. I was one of the Senior Managers and found it very stressful being back. I was able to work from home but in the end work stress contributed to another relapse and I knew I had to make a change. I took some time out and decided to start my own business. A year later it is one of the leading companies in Australia.

I tell all my clients that I have MS so that they understand my situation is sometimes out of my control and can support me. Everyone is compassionate and understanding. They know that when it gets hot I need to stay indoors and stay close to the air conditioning. If I'd stayed in my other job my MS probably would have progressed much more – I felt completely burnt out. For me it was so important that I still worked and now I'm in control of the gears so I can rev up and slow down as and when I want.

Claire, 34 years old

Reviewing your rights

It is important to be fully informed about your rights in the workforce.

You may wonder if an employer can terminate your employment simply because you have MS. This is most certainly not the case and would be classed as unlawful discrimination as well as unlawful termination.

An employer can only terminate your employment if you can no longer perform the core requirements of your job. However, under the *Fair Work Act*, your employer must take reasonable steps to try to accommodate you in the work place. For more information about legal and financial matters, get in touch with your local MS Society.

Seeking work

If you are looking for work and are unsure about how to approach information about your MS, the same guidelines around disclosure apply. However, as many of us now have a significant digital presence, a potential employer may discover you have MS if they look you up online. In this situation, remember that debunking the myths around MS may be your best way forward.

There are also specialist Employment Services available to assist you if you experience difficulty finding employment specifically due to MS. These Disability Employment Service Providers can help you to prepare for work and look for suitable jobs.

Further information

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