

At work with MS

managing life and work

Multiple
Sclerosis
Trust

MS



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Second Edition

We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

MS Trust information service

Helping you find the information you need

The MS Trust offers a wide range of publications, including a newsletter Open Door, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for Open Door and much more visit our website at www.mstrust.org.uk

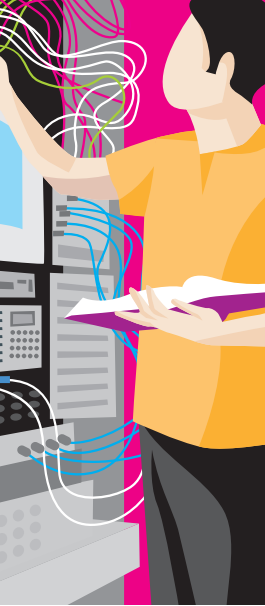
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Introduction

Work occupies a large part of our lives, it means different things to us at different times, but some of its meanings can be summed up as follows.

Work can:

- help us be financially independent
- give a structure and routine to our days and weeks
- encourage us to be active
- give us goals to aim for
- provide social contact outside our immediate family and put us in touch with society at large
- improve our skills
- form part of our identity and provide personal status, self-esteem and confidence.

Research by the Work Foundation¹ has found that people with MS in the UK lose an average of 18 working years and that 75% of people felt the condition had impacted on their employment or career opportunities.

People may leave work for many reasons:

- lack of information and support regarding work at diagnosis
- neither the individual nor their employers know what can be done to help them stay in work
- other priorities – to spend more time with family, or doing other things

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- the same problems as the general population – companies can close down or reduce their workforce
- Government support schemes don't always match the needs of people with variable or progressive conditions like MS.

Not everyone has the same experience of MS, nor the same experience of work. However for a successful working life individuals need to think proactively about their careers and the adjustments they may need to make to continue.

In this book we have tried to include different viewpoints, many from the people with MS who took part in our research project that examined employment and MS². Where views may seem to conflict, we hope this shows there is more than one way of looking at things.

We hope that some of the information will be useful and relevant to you, and that you can dip into it at different times. There is further information about working with MS including interactive tools and the experiences of people with MS at work in the online resource www.mstrust.org.uk/work.

“Remember that you were a valuable asset to the workforce before diagnosis and that hasn't changed.”



1. Bevan S, et al. Ready for Work: Meeting the employment and career aspirations of people with multiple sclerosis. Work Foundation: London; 2011.
2. Townsend G. Supporting people with multiple sclerosis in employment: a United Kingdom survey of current practice and experience. Br J Occup Ther 2008;71(3):103-11.



How will MS affect my work?

“When MS first affects you significantly you need to understand what your personal MS is doing to you. You have to redefine many aspects of your lifestyle and what is important to you; some changes are harder than others and work is only one of these.”



One of the challenges for people with MS is the variability and unpredictability of the condition. No one knows at diagnosis what course their MS will take. In MS, damage or scarring occurs to the myelin sheath – a layer of fatty protein that protects the nerves in the same way that insulating material protects an electric wire. This damage (called demyelination) disrupts the way in which messages, or nerve impulses, are carried to and from the brain and so it can interfere with a range of the body’s functions and thought processes.

The term ‘multiple sclerosis’ comes from ‘sclerosis’, which means scarring and ‘multiple’, which relates to the sites of the scarring, which can occur in different places throughout the central nervous system (CNS) - the brain and spinal cord. The CNS receives, processes and stores information and initiates instructions for bodily activities.

The symptoms experienced will depend on the position and extent of the nerve damage. In the earlier stages

How will MS affect my work?

of MS, the CNS can often compensate for areas of damage by repairing myelin or by re-routing messages around the problem area. This explains why episodes of symptoms (relapses) can be followed by weeks, months or even years when symptoms improve or disappear (remissions). However, if the area of damage becomes too large, communication with that specific part of the CNS may become permanently blocked.

MS is different for everyone; it is not possible to predict what will happen. Everyone will experience different symptoms at different times and the impact of the symptoms on work will very much depend on the type of work and personal experience of MS.

“I have managed to continue with very little change other than reducing the amount of overtime I do. My advice is to continue as normal as far as is possible without making drastic changes early on and deal with issues as they present themselves.”

“It takes time but you can learn to set personal goals which challenge your MS and its boundaries and that you can always win. The workplace is a good setting for some of these goals.”

“Work helps me stay in the real world and not get consumed by MS.”



Some symptoms which could impact on work include fatigue, problems walking or standing for too long, difficulty in lifting or carrying, the need to go to the toilet more often, and concentrating or remembering things.



At diagnosis

Can work continue?

– don't make decisions in a crisis

On receiving a diagnosis of MS, family, friends and even health professionals might give advice to stop working. This could be because they do not understand the nature of MS or because they want to protect you from stress. People who make big changes or leave the workforce either on diagnosis or at the first major relapse may regret doing so.

This is thought to be one of the reasons that, even though many people with MS never experience symptoms severe enough to stop them working, studies have estimated that within fifteen years of diagnosis 80% are likely to be unemployed.

“I reduced my working hours for two years after I was diagnosed – this was done within 24 hours of requesting it. It took me two years of continual requests to increase my hours back to full time when I was ready – this was very stressful.”



During a relapse or at diagnosis, symptoms may appear to be overwhelming and it can be difficult to see the way ahead. Decisions made in a crisis may not provide the best long term solutions and it is advisable to wait until

At diagnosis

the crisis is over to explore fully all the options available to you. Whilst you may not be able to see the way forward, other people will have a different perspective; seek advice from someone knowledgeable about MS before you make any major decisions, for example your MS specialist nurse or occupational therapist.

“When first diagnosed the consultant neurologist suggested, ‘Don’t take major decisions till you have got used to it.’ This was really good advice.”



On the other hand some people find that a diagnosis of MS can be a good time to really take stock and reassess life, including work.

“When I was diagnosed with MS it was a real wake up call. I was doing a job I didn’t feel was challenging me anymore and the commute was really long – I made a change and it couldn’t have been better.”





At diagnosis

Should I carry on working?

Important issues to consider

- Do you enjoy your job?
- What are your strengths, preferences and interests?
- Review financial issues (including potential disability benefits and possible pensions)



Weigh the costs and benefits to you working, and then decide whether to keep working, get a job, or not work

You've chosen to maintain employment

Job with new employer

Present job



Ensure it is not just a case of "grass being greener"

Do you need assistance or adaptations to do your job / make it easier?

Do you need to disclose that you have MS?

YES

What are your personal feelings about disclosure?

What are the social issues in the workplace?

At diagnosis

- Consider your family needs
- Review which aspects of your job cause you difficulty eg travel, environment, tasks, equipment
- What employer assistance might you benefit from that is realistically available? (You may need advice on this)

You decide not to work, but apply for disability benefits or ill health retirement



Consider what you will do with your time and how you can maintain your social contacts



At diagnosis

Employment rights

– what are they?

The Equality Act 2010 replaced and extended the Disability Discrimination Act. This Act protects anyone who has been diagnosed with MS from the time of diagnosis (whether or not they are currently experiencing symptoms) against unfair treatment and discrimination in the workplace where this is related to their condition.

The Equality Act gives people with MS the right not to be discriminated against:

- when applying for a job – employers cannot ask a job applicant about their health unless and until the applicant has been offered a job
- in the way you are treated by your employers and colleagues
- in opportunities for training or promotion
- in being selected for redundancy.

One of the key provisions of the legislation is that employers are expected to consider making ‘reasonable adjustments’ to tasks or premises for staff covered by the Act. There is no precise definition for what

At diagnosis

constitutes a 'reasonable adjustment' but examples include improving accessibility, changing working hours or supplying specialist equipment. There is more about this in the section ***What adjustments can be made?***

There are some exclusions under the Equality Act and these are people working in the Armed Forces, elected councillors, and certain employees who work on board a ship, hovercraft or aircraft.

Who needs to be told?

People with a driving licence who have been diagnosed with MS must tell the Driver and Vehicle Licensing Authority (DVLA). They will send you a questionnaire to assess the impact of MS on driving performance. The DVLA may need to talk to your doctor about your condition. If there is no medical reason to prevent someone driving, a full licence will be retained. If your job requires you to drive, for example if you drive a heavy goods vehicle or passenger transport, you must inform your employer.

Some employment contracts specifically request that you tell your employer and so it is important that you check.

The decision whether or not to tell your employer can be difficult but you cannot access any adjustments unless you have disclosed that you have a condition covered by the Equality Act. This is explored more fully in ***Telling your employer that you have MS.***



Working with MS

Ready for work¹ suggests that individuals with MS need to be assertive self-advocates of their rights in the workplace and take an active role in managing their MS. It also suggests that you need to think proactively about your career and the adjustments you need to make to continue working successfully. This might include telling your employer about your condition so that you can access timely support and highlight how changes to working practices can maximise your productivity in the workplace.

A number of additional factors are involved in working successfully with MS:

- a positive relationship between employee and employer
- an employer with a knowledge of MS, including the impact of invisible symptoms like fatigue and memory problems, and sensitivity to the employee's needs
- an employee with a knowledge of employment rights particularly the Equality Act
- good workplace accommodations, job modifications and flexibility
- effective management of symptoms.

1. Bevan S, et al. Ready for Work: Meeting the employment and career aspirations of people with multiple sclerosis. Work Foundation: London; 2011.

Telling your employer that you have MS

Excluding the specific employers already mentioned, a person is not currently required to tell their employer about their condition unless there are specific health and safety risks. However adjustments cannot be made unless an employer has been told and early disclosure can be vital if effective and optimal support is to be organised.

For some people the right time to tell their employer is when MS begins to have an impact at work. If you decide not to disclose your diagnosis to your employer and colleagues you should take into account that problems may be ascribed to other causes. For example, if you experience slurring speech or balance problems, people may think you have a drink or drugs problem. Without disclosure you cannot access the adjustments that may enable you to do your job well and this may cause stress. You may also risk getting a record for poor work performance if you experience difficulties and people are unaware of the reason.

If your work requires you to drive a vehicle you may have no alternative but to disclose your diagnosis to your employer. However, where no legal requirement exists you may like to consider the advantages and disadvantages of disclosure.

“The more open about the diagnosis you are, the easier it is to access the support that will enable you to stay in work and continue to enjoy working.”



“Keep at it, and don’t disclose that you have MS until you really feel that you need to.”



“I found sharing my diagnosis of MS with my work colleagues a great relief.”



Working with MS

If you do decide to tell your employer about your diagnosis, the way you do this may depend very much on the culture of your workplace and the relationship you have with your manager and colleagues. It is important to remember that you are a valued member of the workforce and an employer will not want to lose an experienced and loyal employee.

“You have spent a lot of time working and training for the job that you do. MS doesn’t take away all that you have learned. With MS you have to find other ways to use the skills and knowledge that you have.”

However, your employer will be concerned about your ability to do your job and may not understand the nature of MS. Support from a colleague, occupational therapist, MS specialist nurse or a union representative at the meeting when you disclose your diagnosis may be helpful. Be well prepared with all the information you may require.

“I am fortunate to have a flexible, understanding employer who appreciates my input and worth to the business.”



Working with MS

If you tell your employer of your MS then both you and your manager should discuss who else might need to be informed. It is up to you whether or not the entire workforce is made aware of your condition and you have the right to expect strict confidentiality.

“I have been able to carry on working with only one major spell of being off work, but my colleagues’ knowing has been of great support in living with MS at work.”



In a society that generally rates health and fitness highly, remember that some people are not tolerant of difference and MS is often not a well-understood condition. Alternatively, some people may be too concerned for your wellbeing and want to protect you; others could become resentful of the adjustments that are made for you.

“My experience of a smaller company’s attitude to MS was not that good. They helped as much as they could by changing my hours/job role but seemed to then expect everything to be OK and for me to be reliable again.”



Disclosing MS at work doesn’t always happen just once, new colleagues may join and others forget. This can mean dealing again with your own feelings about MS as well as trying to manage your colleagues’ reactions.



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“I almost felt guilty for putting colleagues in the position I did, like how they were expected to respond. It often leads to people feeling the urge to apologise. I didn’t want people to feel sorry for me, or be awkward around me. I was still the same person.”



If you are applying for a new job you are not under any obligation to disclose a diagnosis of MS and an employer is not allowed to ask about health problems during the recruitment process. However an employer can establish if you could take part in an assessment process or be able to undertake functions that are intrinsic to the job.

A Disability Employment Advisor (DEA) can give more advice and support in applying for a job and can also support people who are in work but are experiencing difficulties. Disability Employment Advisors can be contacted through your local Jobcentre Plus.

What adjustments can be made?

Under the Equality Act employers have a duty to consider making 'reasonable adjustments' to make sure you are not put at substantial disadvantage by employment arrangements or physical features of the workplace.

“Learn about the Equality Act, the rights of the employee and the duties of the employer.”



What is reasonable is judged in terms of the resources available to the organisation needing to make the adjustments and any disruption to other people. Examples of the sort of adjustments your employer should consider, in consultation with you, are set out in the Equality Act and include:

- considering how the job is structured eg whether some of the work could be done from home, or could more demanding work be done at “better” times of the day/week
- being flexible about your hours, allowing you to have different core working hours, and incorporating more breaks into your day
- making adjustments to the buildings where you work, the furniture, equipment or tools that you use. This can be as simple as rearranging your workspace or, might include provision of a powered wheelchair at work, or improving access to the building. **Access to Work** can provide an assessment of appropriate changes and equipment and may be able to help with some of the costs of equipment and alterations



Working with MS

- allocating some of your work to someone else or using **Access to Work** to pay a support worker to help with some tasks
- transferring you to another post or another place of work
- providing equipment to deal with practical and/or job related issues. Examples of this kind of adjustment are the provision of digital memo, portable air-conditioning and changes to computer equipment or software.

“In my work it’s OK for me to be in late and catch up at home.”

“Ask for changes that will help you, a desk near the toilets, a quiet office.”

“Insist on your rights such as a parking space near the door.”

“Make them see you are capable of the tasks as long as everyone understands your personal management strategies.”



Working with MS

Other things to consider may be the temperature of the office and appropriate equipment or software to enhance your performance. You should play an active role in discussing these arrangements with your employer. It can be helpful to think about what they might ask or be worried about. You could go through your old job description and honestly assess what bits might be harder for you, and identify some potential solutions. It looks better if you show you have looked at the potential problems and have identified how to manage them.

“You are the expert on your MS and you need to lead the way to resolve issues.”



“Be honest about what you can or can’t do. Offer possible solutions eg a trade off. People respond better to ‘I have a problem and a possible solution’.”

Sometimes there can be a learning process for both the employer and the employee around what might be the best solution. There can be an expectation from employers that the person with MS will come with a definitive set of adaptations and this is not always the case.

Access to Work is a government funded scheme that gives you and your employer advice about adjustments that may be effective and support with extra costs which may arise because of your needs. It might pay towards equipment and can also pay towards the cost of getting to work if you cannot use public transport.



Working with MS

“From an Access to Work assessment I’ve got a better desk, an ergonomic chair and a designated parking space nearer to the entrance. These changes have made a real difference.”

“Yes it is all extra work to ask for adjustments or apply for a grant but it will pay dividends in the end. It is important to persevere even if you’re refused the first time because in that clichéd phrase ‘you’re worth it’.”

What’s really worrying you at work?

It can sometimes be helpful to try and “unpick” what’s really worrying you if you have concerns about work. It can also be useful to help you decide how you can tackle issues, and in what order.

What worries you about work?

I’m making mistakes and not performing like I used to

Can you break this down further into things that contribute to the worry?

I find it hard to concentrate in the office, it’s hot and noisy

I have lots of things to do at once

I get really tired by 2pm, three hours before I go home

I find it harder to learn new things

Working with MS

When you break it down, are there things you could start to tackle, either on your own, or with help?

Yes – I could improve the environment to help my concentration

Pick one of the specific worries and write down as many solutions as you can think of, including people who might be able to help.

I could ask my colleague who sits in the corner by the window if they would mind swapping desks

I could try wearing headphones for some of the day to cut down on extra noise

I could ask for screens around my desk to reduce distractions and some of the noise.

I could ask if I could work from home for some of my hours, so I can be quieter at home.

Pick a solution to try

I don't want to involve other people yet so I'll try wearing headphones

What are you going to do? Set yourself a realistic timescale to try this solution to make sure you get it done.

I'll wear headphones for an hour over the lunch period for the next two weeks to see how it goes

Evaluation – it's really important to think about how it went, if it went well, you can tick an issue off your list, if not think about trying another solution.



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“It helped a bit, but not enough as I can only do this for a small part of the day. I think I need to talk to my manager about moving my desk and getting some screens as a start point.”

This process is similar to the problem solving section from ***MS and me: a self-management guide to living with MS***, which can also give you ideas for managing your life with MS.

Who is on your side?

“The advice my union gave me was to get the most senior person you know “on side” in case middle management are less aware of the Equality Act.”



An occupational therapist can be really valuable in discussing and analysing your difficulties at work and working with you to find ways to overcome them. For example they can work with you and your employer to find alternative ways of doing things, rearranging your workspace and ensuring that symptoms are managed most effectively. Vocational rehabilitation services can also be valuable although they may not be available in all areas.

Working with MS

You might want to encourage your employer to speak to someone with expertise in providing work related support. A number of agencies are available and they are there to support you in your work situation. The Equality and Human Rights Commission provides detailed guidance and advice for you and your employer about whether an adjustment is reasonable or not. Issues for you both to consider include:

- how effective is the adjustment?
- will it significantly reduce my disadvantage?
- how practical is it?
- will it cause much disruption?
- will it help other people in the workplace?
- is the cost prohibitive?

“Be prepared to ask for and accept help. It can be available without you knowing and it’s better to be in work with support than not.”

Some of the adjustments that would be useful to you could help others in the workplace.



Working with MS

“There are environmental issues which affect everyone. I worked in an office where the window did not open and too many people in the room made it hot and stuffy. As the heat affected my fatigue badly, the temperature was reduced so my MS has rectified the problem for everyone.”



The benefits to maintaining you as a productive employee are huge. It is easier for an employer to adjust to a known and valued employee than to face the risk and expense of recruiting someone new.

If you are having difficulty with obtaining adjustments it can be useful to get the support of either your MS specialist nurse, occupational therapist, occupational health advisor, or union representative to have a meeting to discuss how your work could be made easier. The choice of whom you approach for support will depend on the specific circumstances. Health professionals can explain the condition and invisible symptoms such as fatigue, occupational health have expertise in managing health conditions at work and union representatives are there to support you as an individual. Health professionals need to be invited to attend a meeting, and invited

Working with MS

to speak, whereas occupational health and union representatives have more formal roles in workplace meetings. If your relationship with your manager or employer has become difficult you may need to use more formal processes to obtain adjustments.

If you believe that your employer has not made reasonable adjustments and your relationship has broken down you might want to consider action. An informal discussion with your employer about your needs might be enough particularly if it is due to a misunderstanding; however you may need to follow your employer's internal grievance procedure. If you need support you can contact the Equality and Human Rights Commission.



Questions you may have

What happens to my job when I reach the end of one year off sick?

How do you retire due to ill health?

How can I organise returning to work flexibly?

Is it better to go back to work earlier and perhaps take longer to return to full capacity or stay at home longer and wait for more improvement?

There are numerous questions that you may have and the answer to many of these depends on your employer's policies and the relationship you have with your employer. The key is maintaining contact with the relevant person at work rather than just sending the required paperwork. Keeping people informed will allow dialogue and negotiation to find the best solution for everyone.

"I have found it is essential to open the lines of communication with your manager to talk about what you can do, so there is not just an assumption about the things you can't manage."



Your employer may have a return to work policy that includes a phased return to work programme, usually over a set time scale. However, if this is not suitable for you, discuss it with your GP as part of your fitness to

Questions you may have

work certification, your employer or Disability Employment Advisor from Jobcentre Plus. A return to work policy that is not modified to suit your condition could be challenged under the Equality Act. By building up your hours and duties over a period of time you should be better able to sustain your return to work rather than trying to return too quickly and risk overdoing things.

Think about how you can build up your stamina for daily activities before returning to work.

Think about how you will manage any symptoms that are new or have got worse, particularly in relation to your work tasks and your work environment.

Think about how you will manage home-life demands once you return to work.

When there is a time of change, either in symptoms or how you manage them, or a change in your job, this may require further or different adjustments and can be a time of renegotiation. Change in management within an organisation can be a difficult time if the new manager does not fully understand adjustments that have been made. It is best to take action early and contact the Disability Employment Advisor or other support rather than allow problems to escalate, when communication could become more difficult. Problems can appear too big to resolve when you are in the middle of things; sometimes talking things through can help to break down the problems into more manageable pieces.



Balancing work and life

The government has been promoting good practice in balancing work and home life and a study found that 91% of employers agreed that people work best when they can balance their work and other aspects of their lives.

“Help once or twice a week at home would make working life a bit easier.”

“It’s all about striking a balance between work, family and social life. Through trial and error you will find what works for you.”

“In my case it is always a rest to go and sit down at work rather than being at home with my four lovely, lively children!”



“Social contact through colleagues is very important to me.”

“Remember your home life and your health are important - work to live not live to work.”

“Being able to work is a massive confidence boost. Doing the job better than those without MS is a great feeling!”

Looking after yourself is very important. A healthy well balanced diet and plenty of fluids are required to provide optimum energy levels. Poor nutrition can worsen existing symptoms such as fatigue and weakness.

Balancing work and life

Doing tasks more slowly or taking regular breaks can help to stop fatigue from building up. It may be possible to achieve more in a series of shorter chunks of work with periods of rest between. Using energy effectiveness strategies – thinking through tasks to see if there are ways of tackling them in a more energy efficient way - can also be useful. You might, for example, consider using taxis instead of driving or using public transport and Access to Work may be able to help with these costs.

“Always stop for lunch and eat something.”

“Use your lunchtime to relax and save some energy, rather than doing the shopping.”

“Try to avoid travelling in the rush hour.”

“Ask about job share before accepting part time hours or change of job.”

“Ensure regular breaks to help fatigue.”

“Try to maximise energy by not doing unnecessary tasks ie prioritise.”

“Do the most important work when you are strongest.”





Changing roles

There are many reasons why you might feel the time is right to leave a job. The nature of the particular job may present more barriers because of worsening MS or you may be looking for new experiences and career challenges.

The workplace may be such that reasonable adjustments cannot be made (perhaps the company cannot afford the alterations necessary; perhaps the alterations would not fit into the existing building). However, if you are considering leaving a job because you feel your employer has not accommodated you, seek legal advice before you resign. This may cost money but the investment will be worthwhile in the longer term.

There are big financial implications if you are leaving paid employment and these should be considered seriously; explore all avenues and examine long and short term aspects. You may be entitled to receive a company ill health or early retirement pension but make sure you read the small print of your scheme prior to making this decision. Voluntary redundancy packages can be substantially less than medical retirement and it is always wise to consult before making a decision. You might consider the impact of a lump sum payment over longer-term smaller increments. Just handing in your notice and leaving work may make applying for benefits difficult.

Changing roles

“If you are considering retirement tell your health professionals and get them to write in support. I got my MS nurse, GP, consultant and vocational rehabilitation team all to write. The weight of medical qualifications impressed the office into action.”



Employment should only be terminated if an employer can prove that MS renders someone incapable of performing their work duties even when accommodations are in place, and other avenues have been explored. However, both employer and employee must take advice, to ensure the process has been managed fairly as failure to do so could be a breach of the Equality Act. Medical retirement could be considered in such an instance.

Working from home

Working from home can be a really good way of sustaining employment. It is particularly effective if you are able to negotiate flexible hours which allow you to take regular breaks, which may not be feasible in your normal workplace. However if you take that step here are some things to consider:

- how will you keep in touch with colleagues and make sure you are included in any social activities?
- are you disciplined enough to take breaks at regular intervals and to stick to your contracted hours, so you don't end up working longer hours than you would if you were at the office?
- keep work separate from your home life – you need to ensure that your home is still your home. Keeping all work activity confined to one room will ensure you can shut the door on it at the end of the day.



Changing roles

“I am finding it difficult to decide whether I can carry on in my job. I have already tried to return to work once, six months after a bad relapse, but my main problem at work was with acute soreness at the back of the head after concentrating, so I went off sick again after only five mornings. When I feel good I think yes I can go back, but when I feel bad with symptoms I think no I can’t. I hope to try again before the end of one year.”



“My previous job entailed a lot of driving; not knowing what job was coming next, nor what obstacles (stairs, parking, distance from car to job) I was going to face next. I found this impossible to cope with. I now do a job that I really enjoy and that provides the right balance. It has totally transformed my outlook on my situation.”

“My work has been greatly affected by MS. I think perhaps if I had been in office work or something that didn’t need fine hand skills and coordination, I may not have felt so down.”

“It can be very difficult to reduce your hours and job role because of MS whilst remaining in the same company. You can easily end up trying to do the same amount of work in half the time in order to try and prove you aren’t any less part of the team.”

Self-employment

Becoming self-employed can seem attractive; you can take control over when you work and what you do. Having greater control can be very positive, however self-employment brings greater responsibility, you have to commit to keeping good records, and keep up to date with any legal requirements. Also if you are not well enough to work, you won't earn any money. There are some insurance schemes which cover illness, but you would need to check if they would cover a condition like MS, and the premium would be another overhead in your business.

There are courses run by the HM Revenue & Customs to help you set up your business and tell you what you need to do. They also have useful information on their website covering issues such as National Insurance, and links to other sites and documents which may be of help. DirectGov also has links to information to help you make an informed choice about whether self-employment is for you.

The social side of work

Work is one of our main sources of social contact. It's probably stating the obvious, but how well you get on with your colleagues can make a real difference to how much you enjoy your job. Having MS can make you worry that if you tell people they will treat you differently. You have to decide what is right for your situation, but if you change your behaviour – for example you stop going out after work or going to special do's because you are tired, people will notice and may treat you differently.

If you change jobs you will have to put in extra effort to establish new relationships which on top of learning about the job can be tiring.

If you decide to stop working, you need to make sure you have a social network independent of work so you don't feel isolated. Just like



Changing roles

someone who might be preparing to retire you need to think how you will spend your time when work no longer provides the structure and routine for your week.

“When seeking work, be true to yourself and be realistic about how many hours you can manage comfortably and the sort of environment you are comfortable in. From my experience it is easy to overestimate and feel deflated later when it doesn’t work out.”

“The most important thing is to find a job that you enjoy doing and that provides maximum job satisfaction.

It may mean less money but the reward is looking forward to work rather than dreading it.”



“Working for myself has enabled me to stay at work; conversely it keeps me at work when I probably should be resting. You can’t tell the clients you have MS – they think you will be unreliable and move their business elsewhere.”

You might want to consider retraining or returning to education. There may be grants available to support study; once again a Disability Employment Advisor will be in a good position to discuss your needs.



Sources of information and support

“Employers need more information about MS and its effect on people.”



People who may offer help and support

Not all these people will be relevant to your situation or accessible in your area.

Occupational Therapist (OT) - An OT can help by discussing and analysing your difficulties at work and making suggestions to overcome them. For example, different ways of doing things, rearranging your workspace, or getting some equipment are all ways in which things could be made easier for you. In some areas an OT may be able to visit your workplace. They can also assist you in planning ways to deal with fatigue management, and how to timetable work and home life optimally.

Occupational Health – in the workplace - The kind of services offered by occupational health departments can vary, and not every workplace has one. The occupational health professional may wish to see you before you start a new job if you have disclosed you have MS and can negotiate a phased return to work after being off sick for a while.



Sources of information and support

Disability Employment Advisor (DEA) – Advisors are available through your local Jobcentre Plus and will provide help and support regardless of your situation. DEAs can also help finding employment and gaining new skills even if you have been out of work for a long time, or if you have little or no work experience.

Human Resources/Personnel – in the workplace

– Larger employers have these departments that help managers understand the responsibilities of the employer under legislation and in following their own procedures. They can facilitate communication between you and your manager.

MS Specialist nurse – An MS specialist nurse provides specialist clinical advice and support to people with MS. They often act to coordinate services for people with MS and can refer someone on to an occupational therapist or other appropriate services.

Union Representative – If you belong to a union, the representative can support you if you have difficulties at work. For example you might need support if your workplace sickness policy doesn't recognise the kind of problems MS causes. The union representative will also know your legal rights in the context of your workplace.

Work Psychologist – You may be referred by the Disability Employment Advisor for an assessment of your employment needs.

Sources of information and support

Organisations

The MS Trust Information Team – Provide a dedicated personal enquiry service offering positive constructive health information for anyone affected by MS. We can also provide relevant information about MS for your employer or colleagues.

Freephone: 0800 032 3839

(Lines are open Monday to Friday 9am-5pm)

Email: infoteam@mstrust.org.uk

Access to Work

Access to Work can help you if your health or disability affects the way you do your job. It gives you and your employer advice and support with extra costs which may arise because of your needs.

www.directgov.co.uk

Citizens Advice Bureau (CAB)

Offers free independent advice on employment rights through a network of local offices.

www.nacab.org.uk

Disability Law Service (DLS)

A national charity providing free, confidential legal advice about social welfare and disability discrimination law for people with a disability and their families. The charity has a designated MS legal officer.

0207 791 9800

www.dls.org.uk



Sources of information and support

Department of Work and Pensions (DWP)

A government department that aims to ensure people with health conditions and disabilities are able to optimise work opportunities; provides details of Jobcentres, benefits and schemes.

0207 712 2171

www.dwp.gov.uk

Equality and Human Rights Commission

An independent body with a statutory remit to promote and monitor human rights, to protect, enforce and promote equality and challenge discrimination.

www.equalityhumanrights.com

Employers' forum on disability

An organisation that aims to enable companies to become disability confident by making it easier to recruit and retain disabled employees.

www.efd.org.uk

Jobcentre Plus

Jobcentre Plus provides access to Disability Employment Advisers (DEA) and the Access to Work scheme.

www.direct.gov.uk

Law Centres

Provide a free professional legal service to people who live or work in their catchment areas.

0207 387 8570

www.lawcentres.org.uk

Sources of information and support

Momentum Scotland

A not for profit organisation that helps people in Scotland who might otherwise be excluded gain skills, training and experience to help find employment.

0141 221 2333

www.momentumsotland.org.uk

Point of Diagnosis

Online resource produced by the Department of Work and Pensions that provides information for people with MS about the protection from discrimination offered by the Equality Act.

www.pointofdiagnosis.org.uk

Working Life Service

Offers guidance and support about workplace issues to people affected by neurological conditions and will work with employers to advise on responsibilities under the Equality Act.

0151 298 3282

www.neurosupport.org.uk

Work Life

An online resource produced by the Department of Work and Pensions in collaboration with a number of charities, employment organisations and health professionals to help people with long-term fluctuating conditions to remain in work.

www.yourworkhealth.com



Sources of information and support

MS Trust publications you may find helpful

Websites

At Work with MS - online

Interactive tools to help you address problems in the workplace and share the experiences of people with MS at work.

www.mstrust.org.uk/work

StayingSmart

A website for people who want to understand how MS can affect thinking, concentration and memory.

www.stayingsmart.org.uk

Books

- Living with Fatigue
- MS Explained
- MS and me: a self-management guide to living with MS
- MS: What does it mean for me?

Factsheet

- Talking about your MS to family, friends and colleagues.

About the authors

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Gail is an experienced occupational therapist who has worked with people affected by MS for over 10 years. When Gail became aware of the difficulties people experienced at work, she found there was little support and was inspired to research the barriers to employment that existed for people with MS. Results of this research have identified practical steps that can be taken by people with MS, employers and health and social care professionals to achieve a successful working life.

Lynn Fox

Information Officer, MS Trust

The MS Trust is a UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

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Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of this publication.

This publication will be reviewed in three years.

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