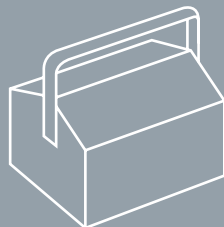


Fourth edition
December 2010

Work and MS

For employees and employers




Includes toolkit chapter

MS

Multiple Sclerosis Society

About this booklet

This booklet is for people with MS and their employers. It also has helpful information for health and social care professionals who work with people affected by MS.

Work and MS looks at working life when you have MS, everybody's rights and responsibilities, the decision to tell people about MS, and 'reasonable adjustments'. It also provides practical tools and sources of support  to help manage the impact of MS.


This information could be useful for people anywhere in the UK, but some of the legal information does not apply in Northern Ireland. Seek local information if you are in Northern Ireland.


If you have recently been diagnosed with MS, you might also want to read the MS Society pocket-sized booklet *Just diagnosed – an introduction to MS* or visit our website to find out more: www.mssociety.org.uk. Our full contact details are on the back of this booklet.

Employers – this booklet has information and tools to help you maximise the potential of people with MS, for your benefit and theirs.

The booklet is split into three parts:

- **Information for everyone**
- **Information for employers**
- **Toolkit** – tables, guides and questionnaires to make everyone's job a little easier

 Where you see this image in the text, check the Toolkit for extra help.

 Where you see this image in the text, you'll find contact details in 'Further information'.

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Part 1

Information for everyone

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The impact of MS

If you have been diagnosed with MS, you are the same person the day after diagnosis as you were the day before – you still have your skills and experience.

But the symptoms caused by MS can vary and fluctuate over time and this can be a challenge at work. Some people find no need for any changes to their job or working pattern; others do benefit from simple adjustments.

It is likely that you will be in the prime of life when you are diagnosed – just when you are of greatest value to your employer. But being diagnosed with MS might have knocked your confidence. You could feel anxious about how to manage your work. You may need some support from your employer to continue to realise your potential. But remember, many people with MS continue to work for years after their diagnosis.

Don't rush into decisions

Don't rush into decisions about your future straight after your diagnosis or a relapse. Give yourself time to think and plan. Consider all your options. 


There can be good reasons to carry on working if you are able to. Research suggests that many people feel better in themselves when they work.¹ And of course, work can bring financial benefits.

Think about the long term as well as how you feel now. Find someone you trust to discuss your options with. This might be a family member, a friend, a colleague or a health care professional.

Remember that for an employer it makes more sense to continue to employ someone with a proven track record than to recruit new staff. Your employer may well have already invested considerable resources in your development. It's good business sense for them to understand your situation and discuss options with you when it's appropriate. Employers also have a legal obligation to support you.


The employer's perspective

Many people know little about MS, or may have misconceptions about the condition. It could be the same for your employer.

Their understanding might not reflect your personal circumstances. You might want to pass on the MS Society publication *What is MS?*, or point them towards information on www.mssociety.org.uk 

MS affects people in different ways, so it is also important that your employer is aware of your specific needs. Any adjustments need to fit your own needs. It is not easy for others to appreciate, for example, that 'fatigue' is not the same as everyday tiredness. Unless you explain, people might not understand the effects of poor coordination, or that at times you find it hard to balance.

¹ Sweetland, J. *et al.* (2007) Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers. *Multiple sclerosis*, 13, 1183-9.

There are often small adjustments at work that can help with all these symptoms and help you to carry on working as before (see 'Reasonable adjustments' page 10). 

Access to Work

Employers may believe that employing somebody with MS will be costly and this might damage their business. However, many people with MS do not need special arrangements and, if they do, these may cost very little or nothing at all. There is practical and financial support for employers and employees from the Access to Work scheme (see page 12).

Should I tell my employer?


Telling people you have MS can be difficult. Some people decide not to disclose their MS at first. Under the Equality Act and the Disability Discrimination (Northern Ireland) Order, if you are already employed when you are diagnosed, you usually do not have to tell your employer.

There are some exceptions:

- if you work in the armed forces
- if you work on planes or ships
- if your employment contract says you need to disclose your diagnosis
- if your MS might have some impact on health and safety in the workplace
- if you are asked directly if you are 'disabled' (because by law a diagnosis of MS means you are considered 'disabled')

If you drive

You may need to tell your employer if you drive as part of your job. The company's insurance policy might need adjusting.

If you drive, you have to tell the DVLA (the DVANI in Northern Ireland) – whether you drive as part of your job or not. They will ask for medical reports from your GP. Often, people with MS who are 'fit to drive' are given a one, two or three year licence. This needs to be renewed after this time. These short-term licences are common for people with any condition which could change over time. 

If the DVLA or DVANI restricts your driving licence, and you use a car as part of your job, you need to tell your employer. If you don't tell your employer about any restriction, this could be a dismissable offence.


How soon should I tell?

Some people don't disclose their MS until their symptoms begin to have an impact on their work and they need their employer to make certain adjustments.

This can put a strain on you and your employer. If your employer and colleagues do not know about your MS, they may wrongly interpret your symptoms. For example, they might assume that a problem with balance is related to alcohol.

But if you don't legally need to tell them straight away, finding the right time to disclose is not always easy.


If you do tell your employer

Take time to think about when and how you will tell your employer, and who you want to involve. This can be a challenging thing to do. It needs courage and risk-taking just when you might be feeling uncertain about what your diagnosis will mean for you. So think about it carefully before you do anything. 


The way that you disclose will depend on the relationship you have with your employer and colleagues, and the nature and atmosphere of your workplace. It is often helpful to bring someone with you – such as your trade union representative, occupational therapist or MS nurse. They might be able to answer questions you are unsure about.

Even if you just have an informal chat with your employer, write to them to arrange the meeting or to summarise what you discussed. Keep a copy so you have a record of the date you first told them about your MS.

Your employer is likely to ask about the impact that MS will have on your work. Maybe take along a copy of this booklet, or other relevant information. It might sound strange, but you could also find it helpful to practise explaining MS and how it affects you. You might do this with a friend or family member.

Think about your specific needs, so that your employer can make adjustments to meet them. There are examples of adjustments on page 11 which you might find helpful. You might want to make a list of useful adjustments. Having a list in any meeting helps ensure you cover everything you need to. 

Remember, you know what and how much you are capable of doing. And don't push your body beyond its limits by denying reasonable adjustments that may be helpful. A small adjustment to your working day or environment could make a big difference.

When you tell your employer about your MS, remember that the meeting is about your work. It is a chance for you to show that you understand your role and to explain what you can about your MS. An overly emotional meeting will not be useful for either party. Tears and sympathy can make it harder to discuss practical matters, so try to keep to an agenda. 

Who needs to know?

Telling your employer does not mean that your diagnosis has to be public knowledge. But you might want to tell some or all of your colleagues. If people do not know, they might think you are getting preferential treatment. If they do know, they are better placed to give you support and help.

People with MS have met with different reactions from their colleagues – some have been indifferent or negative, others want to know how they can help, and some try to be over-protective. It could be helpful to talk with your employer about whether, what, and how to tell your colleagues.

Remember that telling people about your MS is a process rather than a one-off event. You might need to be assertive about your needs if your colleagues or employer focus too much on your disability rather than your ability. Remind them that MS is just one aspect of your life. You are still the employee and colleague you were before they knew about your MS.

Support from professionals

Specialist social and health care professionals can help find the best ways to manage your MS and work.

Occupational therapists

Occupational therapists (OTs) help people participate in everyday life as independently as possible. Some OTs specialise in supporting people in work. They can help you identify problems at work and find ways to overcome them. To offer the right support and symptom management, they will work with you and your employer.


OTs work in the NHS and in social care services. Some may be able to visit your workplace. Your doctors, MS nurse or other care professional can refer you to an OT. You can also find one privately through the College of Occupational Therapists. [**i**](#)

Occupational health professionals


Occupational health is a branch of medicine that looks at health and work, and how one affects the other. Some companies have an occupational health department or access to an occupational health service. You might find it helpful to see an occupational health doctor or nurse when you start a new job, or if you have had an MS relapse.

If your employer has an occupational health department, you may want to tell them first. The occupational health adviser will not necessarily tell your employer about your MS – the information occupational health keeps is usually confidential. You can ask them who they would share information with beforehand if you are concerned.

Time off work

Putting in place the right adjustments can be a real help to staying well and at work. But if you do need to take time off work, it's vital that you keep a good record of your sick leave. This includes noting if you are off because of your MS or for some other reason. A simple table like the one in the Toolkit might help. 

It's good to understand your employer's sick leave policy. This will tell you how much sick leave you are entitled to before you receive **statutory sick pay** instead of your usual pay. It will also explain whether you have a 'rolling years' policy, or whether your sick leave is worked out by the calendar year. It is also worth discussing with your employer and agreeing with them how they will record time off as a result of your MS. Some employers may agree to record this separately as 'disability leave' rather than as sickness absence.

For more about statutory sick pay, contact Citizens Advice.  Your human resources department, line manager or union should be able to explain your organisation's policy.

Recruitment

Understandably, some people are concerned that if they disclose MS, they may be at a disadvantage in recruitment. Where the recruitment process allows you to choose when to mention your health, it might be sensible to wait to tell the employer until a decision has been made. By doing this, there is less chance that it could adversely affect the selection process.

What the law says

An employer can ask for information about a disability during recruitment – this is not against the law. But this information should only be sought if it is necessary for:

- equal opportunities monitoring
- helping disabled candidates in the recruitment process
- checking if applicants can carry out vital tasks of the role (taking into account reasonable adjustments that could be made)

Asking about disability should not be part of the application form. The same applies to questions about sick leave. An employer is not allowed to use questions about disability to discriminate against a disabled person. These kinds of questions should only be asked if they are specifically relevant to the person's ability to do the job.

Are you ‘disabled’?

During recruitment, if you are asked **directly** whether you have a health condition, you need to say that you have MS. This is because you cannot lie to an employer or potential employer.

If you are asked if you are ‘disabled’, you also need to answer honestly. But many people with MS do not consider themselves disabled. If asked in **general terms** whether they have a disability, they would honestly say no.

But if you are asked if you are disabled **for the purposes of the Equality Act (or the Disability Discrimination (Northern Ireland) Order)**, you need to say yes. This is because everyone with MS is automatically covered by these laws and the term ‘disabled’ has a specific legal meaning.

It is important that employees and job applicants do not lie. If information is withheld and it comes out at a later stage, the employer could reasonably assume that the person was hiding information. On that basis, the employer might be justified in dismissing the employee.

The law

Under employment law, all employees and employers have certain responsibilities. You can get information about these general employment rights from various sources, including the Department for Work and Pensions, your trade union, Citizens Advice and ACAS (the Advisory, Conciliation and Arbitration Service). [**i**](#)

As well as this, your contract and other documents such as an employee handbook will have information about your organisation. Ask your human resources department or trade union representative for these if you don’t have them.

As well as these laws and regulations that apply to everyone, if you have been diagnosed with MS you are covered by the Equality Act (in England, Wales and Scotland) or by the Disability Discrimination (Northern Ireland) Order. The Equality and Human Rights Commission and the Equality Commission for Northern Ireland have more information. [**i**](#)

People with MS are automatically covered by these laws from the moment they are diagnosed. They apply whether the company you work for is large or small. The laws do not cover the armed forces, or those working wholly or mainly outside the UK. If you are in the armed forces, Mutual Support, one of the MS Society’s national support groups, can provide information and support. [**i**](#)

The law is complex. This booklet gives a brief overview, but before deciding on any action, speak to a legal or human-resources professional.

The Equality Act and the Disability Discrimination (Northern Ireland) Order

Both make it unlawful to discriminate in all aspects of employment – in recruitment, selection, training, promotion, redundancy and dismissal. They prohibit discrimination in several ways, including:

Harassment – when an employer allows or carries out themselves ‘unwanted conduct’ related to an employee’s disability. To count as harassment, this unwanted conduct would violate the person’s dignity or create a hostile or intimidating working environment.

Direct discrimination – when someone is treated worse than another person because they have a disability (or other ‘protected characteristic’ under the Equality Act).

For example, someone with MS is overlooked for promotion because their employer assumes their MS means they can’t manage staff. An industrial or employment tribunal would need to decide if someone with the same experience and skills but without MS would get the promotion. See page 13 for more on tribunals.

Indirect discrimination (not Northern Ireland) – when the way an organisation or service works is unfair. The discrimination happens because the standard practice of the organisation is unfair when applied to everyone.

For example, a company does not provide job applications in large print. This could be unfair for anyone with sight problems.

Discrimination arising from a disability/ disability-related discrimination – when someone is discriminated against because of something connected to their disability, not because of the disability itself.

For example, a person with MS is dismissed because they take more sick days than others.

‘Discrimination arising from a disability’ applies in England, Wales and Scotland. ‘Disability-related discrimination’ applies in Northern Ireland. The exact details differ.

Protection if you take action – it is also against the law to victimise a disabled person because they have taken action in relation to these laws, or because they might want to do so.

Disability by association

The Equality Act also protects people who have an association with a disabled person – for example, a partner or a carer. A person with an association can bring a claim for direct discrimination or harassment.

For example, the partner of someone with MS is refused an apprenticeship because the employer presumes they will have too many caring responsibilities.

Can an employer ever justify discrimination?


The Equality Act and the Disability Discrimination (Northern Ireland) Order say that sometimes an employer can legally justify discrimination. Direct discrimination cannot be justified by the employer. But it is sometimes possible for an employer to justify some other forms of discrimination, such as ‘indirect discrimination’ or ‘disability-related discrimination’.

Broadly speaking, an employer can justify discrimination if they can prove that a legitimate aim is being pursued and that the steps being taken are a proportionate means of obtaining that aim. What is ‘proportionate’ could depend on the type of job, the size of the company and the impact of the disability on the employee’s ability to do the job.

If an employer fails to make ‘reasonable adjustments’, they would probably find it difficult to show that they treated their employee proportionately.

Reasonable adjustments

Many people with MS never need workplace adjustments, but the Equality Act and the Disability Discrimination (Northern Ireland) Order say that anyone with MS can ask their employer for reasonable adjustments to their job.

These adjustments are to make sure the job is no harder to do than it would be for a non-disabled person. 

Disability Employment Advisers (through JobCentre Plus) can provide support and advice. 

Examples of reasonable adjustments

Many adjustments relevant to people with MS are not expensive. Some cost nothing at all.

- enabling you to take more regular breaks
- providing a place where you can rest for short periods during your working day
- flexible or reduced working hours
- moving your work station further from a source of heat (this might help with fatigue) or nearer to a toilet
- allocating some of your work to someone else
- allowing time off for medical appointments
- assigning you to a different role in the organisation
- arranging for meetings to be held at a time or place to suit you
- a flexible working pattern which enables you to do some of your work from home
- giving you a car parking space by your nearest entrance to work
- improving physical accessibility – for example, by providing handrails or a ramp
- a larger computer screen for people with visual problems
- voice-recognition software or an adapted keyboard or mouse if you find typing difficult
- improved lighting
- a special chair if you cannot stand for long periods
- providing written materials on different coloured paper which can help with some visual problems

What's 'reasonable'?

When considering whether an adjustment is 'reasonable', the employer can take into account:

- how effective it would be in improving the situation
- its cost
- how feasible it is
- the availability of resources (money, equipment and people)
- the type of activity a business undertakes
- how long you have worked or are likely to work for the organisation
- the size of the organisation

There is no limit to the number of adjustments that you can ask for. There is also no limit on how often you ask for them. There may be times when you need to ask for several in a short space of time. There may be several years where you don't need to ask for any. Whenever your needs change, you have the right to ask for adjustments. Your employer cannot pass the cost of any adjustments on to you.

Employers might be able to get financial support for reasonable adjustments through the Access to Work scheme (see page 12).

Access to Work

Access to Work is a scheme to tackle the practical obstacles disabled people might meet at work. As well as advice and information, it can help pay towards the extra costs of employing someone with a disability.

Access to Work can help pay for:

- the additional costs of travel to and from work (for example, if you need to use taxis)
- changes to equipment you use at work
- changes to the premises or the working environment
- a support worker to help with practical tasks at work (for example if you have visual impairment or difficulty using your hands)

Finding an Access to Work adviser **i**

There are two ways to contact an Access to Work adviser:

- Find your local adviser and call them yourself. The DirectGov website www.direct.gov.uk has contacts for Access to Work teams. When you call, you will need your National Insurance number. Also, you will be asked questions about your health, so make sure you are somewhere you can talk openly.
- Ask a Disability Employment Adviser at your local Jobcentre Plus office to contact Access to Work on your behalf.

However you get in touch, you might need a supporting letter from one of your medical team (GP, MS nurse or OT, for example).

Other schemes that might help **i**

There are other schemes and organisations which might help you find or stay in work. These include Work Choice and the Working Life Service, Working Health Services Scotland, Pluss, the Shaw Trust and Remploy. See 'Useful organisations' for contact details, or ask a Disability Employment Adviser for more information.

What if I feel I am not being treated fairly?


Not everybody with MS has a totally positive experience of work. There can be different hurdles. It might be a line manager who fears that a disabled person will be a drain on resources or prevent targets being met. Or colleagues who think that you are getting preferential treatment, or not making a full contribution to the team effort.

Whatever the situation, if you have concerns, there is a process to go through. Here it is in summary. People often find the problem is resolved in the early stages.

Talk informally

Whatever your concerns, you should discuss them with the people involved. Informal discussions are usually the best starting point and can resolve many issues.

Talk formally

If informal approaches do not improve things, you should raise the issue in a more formal setting. 

The best person to speak to will depend on the size of the organisation.


Write with your ‘grievance’

If the conversation is difficult to arrange, or does not bring the results you had hoped for, write to your employer complaining that you are experiencing discrimination (worse treatment than other employees).

This is known as a ‘grievance’. It must be sent to your employer within three months of the date of the discriminatory act.

Note that the deadline to submit a claim in a tribunal is also three months since the discriminatory act (see below).

The employer should then arrange a meeting with you to discuss the grievance, where you can be accompanied by a colleague or trade union representative. If your grievance is dismissed, you must also be given a right of appeal against the decision.

You should also consider sending your employer a Disability Questionnaire, which you can get from the Equality and Human Rights Commission or the Equality Commission for Northern Ireland. 

This questionnaire asks your employer questions to find out why they have treated you worse than others (‘less favourably’). The answers will help show whether you have experienced discrimination. The questionnaire has to be issued within three months of the discriminatory act. The employer has eight weeks to respond.

Issue a claim in a tribunal

If you are not satisfied with the result of the grievance or questionnaire, or if you don’t get a response, you can issue a claim for disability discrimination in an employment tribunal or industrial tribunal (in Northern Ireland).

Once you have issued a grievance, you should wait 28 days before issuing a claim – to allow for a reply to your grievance. But if you want to issue a claim in a tribunal, you will also need to issue this within three months of the discriminatory act – even if the grievance procedure has not finished. The three-month time limit for issuing a claim in the tribunal is strict.


If you didn't put your grievance in writing you will still be able to make a claim, but your award may be reduced by the tribunal.

If you decide to make a claim at a tribunal, you get a second chance to submit the Disability Questionnaire. This usually has to be done within 21 days of submitting your tribunal claim. A questionnaire can be submitted after the 21 days have passed, but only with the permission of the tribunal.

Where to get help

The MS Society funds an MS Legal Officer at the Disability Law Service (DLS). The Legal Officer can provide information and can also arrange for you to speak to a specialist employment adviser who can help with all aspects of employment law and disability in England and Wales. The DLS can help enquirers from Scotland and Northern Ireland to find legal organisations in those parts of the UK. Call them to make an appointment with an adviser. You can have the appointment by phone or email. You might have to wait a week or two for your appointment. **i**

If a job is
no longer
suitable

If, with reasonable adjustments, you find your current job is no longer suitable, you might want to consider alternatives. 

These could include:

- Another role within the organisation.
- Becoming self-employed. If you have, or are willing to develop, the appropriate skills, this might be an option. In general, a self-employed person has more control over the volume and pace of their work.
- A different career which might involve retraining. Financial support for retraining might be available through Access to Work.
- A sabbatical – some employers allow their employees to take an unpaid break so that they can pursue a personal interest or explore a potential new direction.
- Voluntary work.
- Retirement.

Get support, information and advice before you make any decisions – from organisations such as those listed at the back of this booklet, your trade union, and the MS Society. **i**

Part 2

Information for employers

What is MS?

How might MS affect an employee's ability to do their job?

Does the employee now represent a poor investment?

Communication

Help for employers

The information below is intended to help employers understand their employee with MS, what their needs might be, and how to maximise the potential of people with MS for the benefit of both employer and employee.

What is MS?

MS is the most common disabling neurological condition affecting young adults. It affects around 100,000 people in the UK.

The majority of people with MS are of working age when they are diagnosed. Employment is therefore likely to be a major issue for many of them.


MS is an unpredictable condition and its effects vary considerably between individuals. Symptoms can include difficulties such as numbness and altered sensations, impaired balance, fatigue (especially in warm temperatures), or poor coordination. For many people, it is a fluctuating condition and an individual may have significant periods when they are free from disabling symptoms.

Find out more at www.msociety.org.uk or call the freephone MS Helpline on 0808 800 8000 (weekdays 9am-9pm).

How might MS affect an employee's ability to do their job?

Many MS symptoms are invisible – such as fatigue and numbness. Employees with MS might be experiencing a range of symptoms in the workplace which are not obvious and are difficult to understand and explain.

Like those with other disabling conditions, people with MS aim to manage their symptoms in a way that minimises its impact at work. Many will need only minimal assistance from their employer or colleagues to carry on meeting the demands of their role.

But some employees do need to make changes in the way they work or in the type of work they do. Often, this does not happen until several years after diagnosis, allowing time for both the employer and employee to plan for this possibility. 

Does the employee now represent a poor investment?

Being diagnosed with MS does not alter the person's knowledge or skills. As an employer, you may well have invested considerable time and resources in developing the individual. It makes good business sense to continue reaping the benefits of that investment.

Reasonable adjustments

The Equality Act 2010 and Disability Discrimination (Northern Ireland) Order place a duty on employers to put into place reasonable adjustments that a disabled person can request if any aspect of their working arrangements, or the building or place of work, make it more difficult for them to do their job (compared with a non-disabled person).

Many adjustments requested by people with MS will be inexpensive, or cost nothing, and cause minimal disruption. The Access to Work programme might help with financial and practical support for adjustments.

See page 10 – ‘Reasonable adjustments’ – for examples which have helped people with MS, and how to decide what’s ‘reasonable’.

It should be relatively simple for most employers to make appropriate adjustments that meet the needs of an employee with MS. Taking this action might also avoid the trouble and expense of a grievance or tribunal. Should a person with a disability make a complaint to a tribunal, a successful claim would be likely to prove expensive for the employer. Theoretically there is no financial limit on a discrimination award.

Communication Many employees feel anxious about telling employers about their condition. But since it is hard to help if the diagnosis is kept secret, it is in the employer’s interest to encourage people to disclose any disability.

An organisational policy which gives guidance on who to contact and how this might be done – assuring confidentiality – might be an encouragement. Having transparent and easy-to-find policies in general can help employees feel confident in their situation.

If an employee does want to discuss their condition, it might be helpful to invite them to be accompanied at the meeting. An MS nurse or occupational therapist will be able to provide further information on the condition and its implications for employment. They can also be a valuable support.

At certain times, such as shortly after diagnosis, after a relapse, or at the onset of new or recurring symptoms, people with MS may feel exceptionally vulnerable, unsure of their own abilities and reluctant to talk about their future. Persuading someone **not** to make an important decision at such a time may be part of the employer’s role.

Confidentiality is clearly essential. If an employee has chosen to share information with you it does not mean they have told anyone else. It’s vital this trust is not broken. But it could be helpful to discuss with the employee whether and how colleagues might be informed of their condition – and how you can support them in this. A Disability Employment Adviser, occupational therapist or MS nurse can provide helpful advice and support in this area.

Help for employers

As an employer, it is important to understand your legal obligations. Everyone with MS is automatically covered by the Equality Act or Disability Discrimination (Northern Ireland) Order. Although many people with MS never need adjustments, some people do.

The Employers' Forum on Disability (EFD) is a national organisation helping employers to recruit and retain employees with disabilities. It represents organisations that employ around 25 per cent of the UK workforce. The EFD is an invaluable source of information and advice and produces a wide range of materials for employers. The EFD wrote the 'Workplace adjustment agreement' in Part 3 of this booklet. Contact EFD on www.employers-forum.co.uk or 020 7403 3020.

In England, Wales and Scotland, the Equality and Human Rights Commission publishes guidance on all aspects of discrimination in employment for employers, advisers and employees. New statutory codes have been produced by the EHRC on the Equality Act. Contact EHRC on www.equalityhumanrights.com or call 0845 604 6610 in England, 0845 604 8810 in Wales, or 0845 604 5510 in Scotland.

The Equality Commission for Northern Ireland offers similar information and support – www.equalityni.org or call 02890 890 890.

To find out more about multiple sclerosis, contact the MS Society on www.mssociety.org.uk or ring the freephone MS Helpline on 0808 800 8000 (weekdays 9am-9pm).

Part 3

Toolkit



Meeting and planning – for employees and employers

Workplace adjustment agreement – for employees and employers

Understanding your work situation

Time off work

Return to work after time off sick

Finances – reducing your hours

Wanting to change current work

Useful contacts

Further information

This section contains a number of useful tables, questionnaires and guides – for employees and employers. They have been put together as a result of research at the Institute of Neurology, University College London and the National Hospital for Neurology and Neurosurgery. This research looked at supporting people with MS to stay in work.

The full toolkit used in the research, called *Working yet worried*, is available to download or order from www.mssociety.org.uk. If you don't have access to a computer, call the UK Information Team on 020 8438 0799.

Meeting and planning – for employees and employers

Good communication between employee and employer can really help to manage the effects of MS at work and avoid misunderstandings. The following tables and guides might help with planning and recording meetings.

Employees can be understandably nervous about discussing their MS, so having notes and planning ahead can help to control their anxiety and keep the meeting focused.

Notes from the meeting

Why use this?

Accurate notes mean that everyone has a record of what was discussed.

As well as this record, it is always useful to have an agenda, setting out what will be discussed.

It is really helpful to have a note-taker at meetings. They might be a health care professional who has been providing work-related support, a trusted colleague, or a union representative.

Sometimes, there is no one who can attend as a note-taker, or an employee would rather meet alone. In this case, employers might usefully allow the meeting to be recorded on a dictaphone. This also has the advantage that people can listen back if something wasn't clear the first time.

Meeting (date/ time/ duration)

Location

People present (include full name and job title)

Confidentiality stated and agreed? Yes/ No

Agreement on who the information from the meeting can be shared with – if it needs to be shared with others not present (full name and job title)

Summary of what was said (can be helpful to link this to the agenda if you have one)

Action points/ things that need to be completed including date to be done by

Accommodations agreed to be implemented

Minutes written by

Date

Signed

Circulated to

Date

Workplace adjustment agreement – for employees and employers

Why use this?

The 'Workplace adjustment agreement' is a living record of reasonable adjustments agreed between a disabled employee and their line manager.

The agreement can:

- ensure that both parties, the individual and the employer, have an accurate record of what has been agreed
- minimise the need to re-negotiate reasonable adjustments every time the employee changes jobs, is relocated or assigned a new manager within the organisation
- provide employees and their line managers with the basis for discussions about reasonable adjustments at future meetings

Benefits for the employee

The agreement helps you:

- explain the impact of your disability on you at work
- suggest adjustments that will make it easier for you to do your job
- offer further information from your doctor, specialist or other expert
- request an assessment by occupational health, Access to Work or another expert
- review the effectiveness of the adjustments agreed
- explain any change in your circumstances
- be reassured that your manager knows what to do if you become unwell at work and who to contact if necessary
- know how and when your manager will keep in touch with you if you are absent from work because of illness or a disability-related reason

Benefits for the employer

The agreement helps you:

- understand how a particular employee's disability affects them at work
- explain the needs of the business or organisation
- explain the organisation's attendance and reasonable adjustment policy
- recognise signs that an employee might be unwell and know what the employee wants you to do in these circumstances including who to contact for help
- know how and when to stay in touch if the employee is off sick
- consider whether or not the employee needs to be referred for an assessment by an occupational health or another adviser to help both parties understand what adjustments are needed
- review the effectiveness of the adjustments already agreed
- explain any change in the employer's circumstances

Important points about the 'Workplace adjustment agreement'

Review regularly – This is a live document and should be reviewed regularly by both the employee and manager and amended as appropriate.

Seek expert advice – Remember that expert advice from third parties, such as occupational health advisers, Access to Work or IT specialists may be needed before changes can be agreed and implemented.

New managers – New managers of employees with 'Workplace adjustment agreements' should accept the adjustments outlined in the agreement as reasonable and ensure that they continue to be implemented. The agreement may need to be reviewed and amended at a later date, but this should not happen until both parties have worked together for a reasonable period of time.

Workplace adjustment agreement

This statement is a record of an agreement made between
employee name

and
line manager name

and what each party will do in the event of
employee name

displaying symptoms of a relapse or increased problems due to progression of multiple sclerosis. This statement will be reviewed and amended as necessary with the agreement of both parties:

At regular one-to-one meetings

At return to work meeting following sickness absence

At annual appraisals

Before change of job or duties

When there is a change of manager

Before or after any change in circumstances

Employee

1 My disability in the workplace

My MS currently causes the following issues in my work – list problems if any or leave blank (for example, I am exhausted after travelling to work on public transport).

I need the following agreed reasonable adjustments (refer to Access to Work agreement if relevant)

Date budget holder contacted if relevant

Date implemented

I need the following agreed reasonable adjustments (refer to Access to Work agreement if relevant)	Date budget holder contacted if relevant	Date implemented

If I have a relapse or any small changes in my condition or if the adjustments agreed are not working, **I will let you know** and we should meet privately to discuss any further reasonable adjustments or changes that should be made.

If you notice a change in my condition or feel the reasonable adjustments are not working, I would be happy to meet with you privately to discuss ways to manage this within the workplace.

Emergency contacts

If I am not well enough to be at work I am happy for my line manager to contact either of the following emergency contacts:

GP/ consultant name

Telephone

Relative/ other name

Telephone

Line Manager

2 Keep in touch

If you are absent from work on sick leave for more than [] days and have followed the usual procedures for notifying the organisation of your sickness absence I will keep in contact with you in the following way:

Who will contact who?

How will contact be made? (email, telephone, text, letter)

How often? (daily, weekly, monthly)

When? (preferred day, preferred time)

3 Discuss while you are on sick leave

These are the topics we have agreed we will discuss while you are absent, for example:

- how you are feeling
- what I can do to help
- current work
- planned phased return to work
- return to work date

4 Return to work

When you are ready to return to work after a period of sickness absence, we will meet to review this statement and make amendments as necessary.

At this return to work meeting we will also discuss, for example:

- current work issues
- a phased return/ back to work plan
- what to tell the team
- assessments to review existing reasonable adjustments (Access to Work, GP, occupational health) and identify new adjustments that might be needed, and so on

5 Unauthorised absences from work

If you are absent from work and have not followed usual procedures for notifying us that you are sick, I will do the following:

(For example – try to contact you on your mobile, notify your emergency contact whose up-to-date details are as follows...)

An up-to-date copy of this form will be retained by myself/ line manager/ HR

Employee signature

Date

Employer signature

Date

This document was written by the Employers' Forum for Disability. It is tailored to meet the needs of people with MS. A general version is available from their website, www.efd.org.uk

Understanding your work situation

Understanding your work situation

Why use this?

This questionnaire will help you note exactly what you do at work – your role, why it is important to you, and the skills you bring to it. Understanding this will give you a better idea of any reasonable adjustments that might help. You might want to complete this on your own, with an occupational therapist, or other health care professional.

Job title

Employer

Is your employer a member of the Employers' Forum on Disability? Yes/ No

Are you a member of a union? Yes/ No

Time in current role

Time in company

Main responsibilities

Hours contracted

Actual hours

Management structure
(draw diagram – put star by
people you have disclosed to)

Likes

Dislikes

What are your strengths and weaknesses?

Why use this?

Filling in this table will give you a personal 'SWOT analysis', identifying:

- your **S**trengths
- your **W**eaknesses
- the **O**pportunities you have
- the **T**hreats you face

Knowing these could help you:

- Appreciate the strengths of a situation – upon which you can build
- Identify weaknesses which you may wish to try to minimise
- Recognise opportunities so that you can make the most of these
- Be clear about possible threats and treat them in a strategic way

Strengths

What do you do well?
What are your personal strengths? What do others see as your strengths?

Weaknesses

What could be developed? What could you improve? What are others likely to see as your weaknesses? What should you avoid doing?

Opportunities

What good opportunities are open to you?
Can you turn your strengths into opportunities?
What financial/ legislative changes can benefit you in the future?

Threats

What are the barriers to your development? What sort of external obstacles do you face? What threats do your weaknesses expose you to? What change is coming?

Future planning sheet

Why use this?

It can be helpful to write down plans, rather than just thinking about them. Having them written down might make it easier to discuss them with family or friends.

Where are you now?

Where do you want to go?

How are you going to get there?

Time off work

Why use this?

It's vital to keep a good record of any time that you have to take off work. Having this can help with discussions about reasonable adjustments and with your own planning. You could just tick the reasons or put a brief description, such as 'flu' or 'compassionate leave'.

Date off work				
Annual leave				
Sick leave general				
Sick leave MS				
Other leave (eg compassionate, or child-related)				

Return to work after time off sick

Why use this?

This can help you come up with a clear plan for returning to work. If you have been off work for longer than three weeks, it's often a good idea to return gradually – with a 'graded return to work'. Check if your employer has their own time frame for this. If your employer has an occupational health department, you might see them before returning to work.

How long have you been off work?

Have you made contact with your employer? If so who?

What expectations are there regarding your return to work?

What support is available in your workplace to facilitate the return to work (for example, identified relapse plan, union or occupational health support)?

When would you like to return to work?
Is this realistic?
Positive factors identified for returning to work

Concerns identified with returning to work
(consider tasks, social environment,
physical environment, activity tolerance)

Return to work plan – an example for someone who works 9am-5pm

Week	Monday	Tuesday	Wednesday	Thursday	Friday
1		Work 10-2		Work 10-2	
2	Work 10-3		Work 10-3		Work 10-3
3	Work 10-4	Work 10-4		Work 9-5	Work 9-5
4	Full-time hours	Full-time hours	Full-time hours	Full-time hours	Full-time hours

Return to work plan

Week	Monday	Tuesday	Wednesday	Thursday	Friday
1					
2					
3					
4					

Consider how your workload can be adjusted to fit the return to work plan, plus strategies to be implemented to ensure this happens

List the adjustments you would like to help you return to work

Finances – reducing your hours

Why use this?

This can help you think about the financial impact of reducing your hours. People often find that working a four day week, for example, can make a huge impact on levels of fatigue, but has a financial impact which they can manage.

Questions to consider

Be clear about the financial impact of reducing your hours. Also think about how you would manage your work in reduced hours – if your hours are reduced will your work load be reduced as well?

Ask yourself the following questions:

- Can I meet my financial responsibilities if I reduce my income?
- Can I meet the demands of my job on reduced hours?
- Can my work load be reduced if my hours are reduced, or would the same amount of work be required of me?

Current hours contracted to work

Full time

Part time

Actual hours worked (these can differ from the hours you are formally paid to work)

Full time

Part time

Type of contract (for example, full contract, temporary work, paid for hours worked)

Type of work (for example, shift work, regular hours, ad hoc hours)

Benefits (for example, pensions). Are there conditions attached?

	Number of hours	Income after tax (take home pay)
Full time	<input type="text"/>	<input type="text"/>
0.8 full time equivalent	<input type="text"/>	<input type="text"/>
0.6 full time equivalent	<input type="text"/>	<input type="text"/>
0.4 full time equivalent	<input type="text"/>	<input type="text"/>
0.2 full time equivalent	<input type="text"/>	<input type="text"/>

Wanting
to change
current work

Why use this?

Before you decide whether or not to carry on working, think about the actions you could take to make changes in your role.

Why am I not happy in my current situation and considering not working?	Want to work same job – with some changes What needs to change? How can I make this happen?
	Want to work different job but same employer What role would I like? What can I do to facilitate this change?
	Want to work for a different employer Where would I like to work? What role would I like to have? What do I need to do to facilitate this change?
	Leave job and not work How will I manage financially? What do I want to do with my time? What options are open to me?

Useful contacts

Name	Telephone	Support they can offer
Occupational therapist		
Contact in human resources		
Link person at work		
Access to Work adviser		
Occupational health contact		
Disability Employment Adviser		
Other		
Other		
Other		

Useful organisations

Advisory, Conciliation and Arbitration Service (ACAS)

Can help resolve disputes at work.

Telephone 08457 47 47 47
www.acas.org.uk

Access to Work

Access to Work is designed to help employees and employers find solutions to the practical difficulties people face at work because of a disability.

See Jobcentre Plus (page 38).

Benefit Enquiry Line

General advice on benefits.

England, Wales and Scotland
Telephone 0800 88 22 00
Textphone 0800 24 33 55

Northern Ireland
Telephone 0800 220 674
Textphone 0800 243 787

Benefit Shop – Northern Ireland

Information and advice about benefits, including help with completing forms.

Telephone/ Textphone 028 9033 6958/ 6206
www.dsdni.gov.uk (search 'benefit shop')

Citizens Advice

Help with welfare rights, housing and disability advice. Your local office (known as a 'bureau') is listed in the telephone directory and on their website.

To find local offices in England and Wales:

www.citizensadvice.org.uk

In Scotland: www.cas.org.uk

In Northern Ireland: www.citizensadvice.co.uk

Online advice: www.adviceguide.org.uk

College of Occupational Therapists

The website includes details of how to find a therapist, and publications including *Fatigue management for people with multiple sclerosis*.

Telephone 0800 389 4873
www.cot.org.uk

Department for Work and Pensions

Information about general employment rights.

www.dwp.gov.uk

DIAL UK (Disability Information and Advice Lines)

Supports 130 disability information and advice services across the UK. For Scotland, see also **Update**.

Telephone/ Textphone 01302 310 123 (to find your nearest branch)

www.dialuk.org.uk

www.direct.gov.uk/disabledpeople and www.nidirect.gov.uk

Informative government websites covering a range of issues affecting disabled people, including employment.

www.nidirect.gov.uk applies only to Northern Ireland.

Disability Alliance

Publishes the *Disability Rights Handbook* each year and has a website with frequently asked questions on, among other things, work and benefits. For a copy of the Handbook, contact the Alliance, visit the website for an order form or go to www.amazon.co.uk. The Disability Alliance cannot answer individual enquiries.

Telephone 020 7247 8776

www.disabilityalliance.org

Disability Employment Advisers

Contact through your local Jobcentre Plus office.
(see page 38)

Disability Law Service

National charity providing free, confidential legal advice and support in social welfare and disability discrimination law for disabled people, their families and carers. The MS Society funds a dedicated MS Legal Officer who can provide basic legal advice and information and can arrange for an appointment with a specialist employment adviser. Cannot advise on the law in Scotland or Northern Ireland, but will try and signpost to appropriate specialists.

Telephone/ Textphone 020 7791 9800

www.dls.org.uk

DVLA – Driver and Vehicle Licensing Agency

Vehicle licensing body in Great Britain.

Telephone 0300 790 6801

Textphone 0300 123 1278

www.direct.gov.uk (search 'DVLA')

DVANI – Driver and Vehicle Agency Northern Ireland

Vehicle licensing body in Northern Ireland

Telephone 0845 402 4000

www.dvani.gov.uk

Employers' Forum on Disability

National organisation helping employers to recruit and retain employees with disabilities.

Telephone 020 7403 3020

Textphone 020 7403 0040

www.employers-forum.co.uk

Equality and Human Rights Commission/ Equality Commission for Northern Ireland

Information and advice about the Equality Act and the Disability Discrimination (Northern Ireland) Order. Can also offer advice on good practice in the employment of disabled people.

England: Telephone/ Textphone 0845 604 6610/6620

Wales: Telephone/ Textphone 0845 604 8810/8820

Scotland: Telephone/ Textphone 0845 604 5510/5520

www.equalityhumanrights.com

Northern Ireland: Telephone/ Textphone 02890 500 600/ 589

www.equalityni.org

Jobcentre Plus

Contact for details of Disability Employment Advisers and the Access to Work scheme. To find your local office, look in your phone directory or go to www.direct.gov.uk (and search 'jobcentre plus').

Mutual Support

Information and support for serving and ex-serving members of the armed forces affected by MS, their families and carers.

Telephone 020 8438 0856

www.mutualsupport.org.uk

welfaresupport@mutualsupport.org.uk

RADAR (Royal Association for Disability and Rehabilitation)

Campaigning and advisory disability body.

Telephone 020 7250 3222

Textphone 020 7250 4119

www.radar.org.uk

The Pensions Advisory Service

Volunteer advisers throughout the UK. They can also be contacted through Citizens Advice.

Telephone 0845 601 2923

www.pensionsadvisoryservice.org.uk

Pluss

Supports disabled people to find jobs and careers.

Telephone 0800 91 777 92

www.pluss.org.uk

Remploy

Supports disabled people to find employment.

Telephone 0800 138 7656

Textphone 024 7651 5869

www.remploy.co.uk

Shaw Trust

National charity working with employers, social services and disabled people, to help people find work.

Telephone 01225 716 300

Textphone 08457 697 288

www.shaw-trust.org.uk

Trades Union Congress

Information line for general employment enquiries and to find out which union is related to your work.

Congress House
Great Russell Street
London WC1B 3LS

Telephone 020 7636 4030

www.tuc.org.uk

UPDATE

Scotland's National Disability Information Service.

Telephone 0131 669 1600

www.update.org.uk

Work Choice

Government scheme to help disabled people whose needs cannot be met through other work programmes, Access to Work or workplace adjustments. This might be because you need more specialised support to find employment or keep a job once you have started work.

www.direct.gov.uk (search 'work choice')

Work Life

Website with information for people with a long-term condition, employers and care professionals.

www.yourworkhealth.com

Working Health Services Scotland

An NHS service to help employees remain in or return to work quickly. Currently operating across NHS Borders, Lothian and Tayside.

www.healthyworkinglives.com/workplace-health-services-scotland/index.aspx

Telephone

NHS Borders: 01896 825983

NHS Lothian: 0131 537 9579

NHS Tayside: 01382 825100

Working Life Service

Information, advice, guidance and support for people who are affected by a neurological condition and employers. Based in Liverpool, but works in several parts of the UK.

Telephone 0151 298 3288

www.neurosupport.org.uk/working.html

MS Society support

UK Information Team
020 8438 0799
infoteam@mssociety.org.uk

MS Society publications

The MS Society has publications on a wide variety of topics, including information for people just diagnosed, types of MS, managing relapses, and social care services. Find out more and order at www.mssociety.org.uk/publications or call 020 8438 0799 (weekdays 9am-4pm).

MS Society website and members' magazines

Keep up to date with news relating to MS with the MS Society website www.mssociety.org.uk and UK members' magazine, *MS Matters*. Members in Northern Ireland, Scotland and Wales also receive national magazines. To join the MS Society call 020 8438 0759 or go to www.mssociety.org.uk/joinus

MS Helpline

The award-winning MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, the newly diagnosed or those who have lived with the condition for many years. Information about MS is available in over 150 different languages by speaking to a Helpline worker via an interpreter. Call freephone **0808 800 8000** (weekdays 9am-9pm, except bank holidays) or email helpline@mssociety.org.uk

MS Society National Centre, Information Centre

Based at the MS National Centre in London, the Information Centre is equipped for visitors to read or locate books and journals or view videos and DVDs. To request publications, research articles or other information about MS, visit www.mssociety.org.uk/library or call 020 8438 0799.

Local information centres

There are MS Society local information and support centres in many locations around the country. These centres are staffed by volunteers who can help you with information about MS and services in your area. Call 020 8438 0799 for the details of your nearest centre.

Local branches

The MS Society has a network of over 300 local branches across the UK. The branches – run by trained volunteers – provide information about MS and local services, a chance to meet others affected by MS and take part in a range of activities. For more information, check the MS Society website or call 020 8438 0944.

Authors and contributors

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This title will be reviewed within two years of publication.

Lined writing area with horizontal lines and a vertical margin line on the left.

A large rectangular area with a thick dark grey border on the left and bottom, and horizontal lines for writing. The lines are evenly spaced and extend across the width of the page.

MS Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 100,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline, grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS nurses and a wide range of information.

Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds around 80 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters. You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

Contact information

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700

MS Society Scotland
National Office
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676

National MS Helpline
Freephone 0808 800 8000
(weekdays 9am-9pm)
Website www.mssociety.org.uk

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