# M.E. and work

A guide for people with M.E. who are in or actively seeking work, or considering employment in the future





# **Foreword**

There is no doubt that M.E. can have a significant impact upon a person's ability to work. For some, their symptoms are so severe that they are not able to consider working at all, while others may be able to work or volunteer when fluctuating symptoms allow.

Many people of working age are in employment when they first experience M.E. and this can lead to a challenging and uncertain time. In addition to having to come to terms with symptoms and learning to manage them, there is the worry about how returning to and sustaining work can be managed, or whether their job can be held open.

Losing or being unable to work can have an impact across many areas of a person's life, including income, career development and social life. Work can be an important and meaningful activity that forms a fundamental part of person's sense of identity.

Fortunately, a range of professionals with expertise and experience in the field of long-term health conditions and work can support you to seek, secure and sustain employment wherever this may be possible. Seeking well-informed advice to plan and prepare for success doesn't guarantee it will happen but we have found that, for a lot of people with M.E., it has made the crucial difference.

This resource aims to offer key information and signposting for people with M.E. who are in work, considering work in the future or actively seeking work now. We know that, for others, working or training is sadly not an option. Action for M.E. continues to support these individuals through our other support services.

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# You, M.E. and work

Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating, neurological illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. It affects an estimated 250,000 people in the UK, and around 17 million people worldwide.

Within the NHS, a diagnosis of Chronic Fatigue Syndrome (CFS) or CFS/M.E. is often given. M.E. is sometimes also diagnosed as Post-Viral Fatigue Syndrome (PVFS). This can make it confusing for many. Action for M.E. uses the terms M.E., CFS and M.E./CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to M.E. To keep things straightforward, we use the term M.E. consistently throughout this booklet.

People with M.E. experience severe, persistent fatigue associated with postexertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

Not everyone with M.E. will experience the same symptoms. People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Some make good progress and may recover, while others can remain ill for a number of years. Some people find that they don't go back completely to the way they felt before they became ill, but they do recover sufficiently to lead happy, fulfilling lives. This is similar to other chronic illnesses.

As M.E. is a fluctuating illness, symptoms can vary day-to-day as well as over longer periods. This can make it difficult to maintain a consistent level of working, which can be frustrating and challenging for you and your employer.

People who have M.E. tell us that they, their employer and the people supporting them need more information about how to effectively manage M.E. at work. This booklet is primarily for people with M.E. and will be a useful resource for anyone supporting them to achieve their employment aspirations.

This booklet outlines the employment rights and support available for people with M.E., as well as providing advice on seeking, returning to or staying in work. It also offers advice on how to leave your job in the best possible way and what you can do if you do lose your job. It provides information relating to welfare benefits and other work-related finances.

Throughout this booklet we suggest a range of free, expert, impartial services that you might find useful. They are highlighted in green boxes and you can find further details in 'Useful contacts' on p 41.

# The legal context

Your employer's legal responsibilities to you as an employee with M.E. include:

- standard obligations under your contract of employment
- duties under the Equality Act 2010
- responsibilities under the Health & Safety at Work Act 1974.

This booklet and the information given on our website are offered as a general guide and do not constitute an authoritative description of the law, nor should they replace seeking professional legal advice when appropriate.

### **Equality Act 2010**

The Equality Act 2010 is a piece of legislation promoting equality and seeking to prevent discrimination on the grounds of any of the nine "protected characteristics" categorised as age, disability, gender reassignment, marriage/civil partnership, pregnancy/maternity, race, religion/belief, sex and sexual orientation.

The Act defines disability as "a physical or mental impairment that has a substantial and long-term adverse effect on the ability of an employee to carry out normal day-to-day activities."

"Substantial" means more than minor or trivial and "impairment" can include long-term medical conditions and fluctuating or progressive conditions.

M.E. is a fluctuating long-term condition which can have a substantial impact upon a person's ability to attend work and perform their job. *The Equality Act 2010 guidance on matters to be taken into account in determining questions relating to the definition of disability* lists M.E. and CFS as conditions which could meet this definition (this guidance is produced by the Office for Disability Issues; see useful contacts on p 41, or download a copy at www.gov.uk/government/publications/equality-act-guidance).

Therefore, if you have M.E. or CFS, you may meet the Equality Act 2010 definition of a disabled person and have rights under the Act. It is important to note, however, that while you, your employer, or a medical or legal professional may have a view as to whether you are likely to be considered a disabled person with rights under the Equality Act 2010, only a court of law can pass a judgement which actually determines your rights and protection under the Act.

# What does this mean for you?

The Act seeks to protect disabled employees from discrimination, harassment and victimisation (bad treatment of a disabled employee because they have complained about discrimination or harassment) and to do this it specifically:

- places a duty on employers to make reasonable adjustments (see p 13) to help staff overcome disadvantage resulting from a long-term health condition or impairment
- states that it is unlawful to directly treat a disabled person unfavourably because of something connected with their health condition, eg. taking away a job offer because you say that you have M.E.
- states that it is unlawful to indirectly treat a disabled person unfavourably because of something connected with their health condition, eg. changing shift patterns to require all employees to work eight-hour days
- makes it unlawful, except in certain special circumstances, for employers to ask about a job candidate's health before offering them work.

# How does the Equality Act 2010 help protect me?

The Act cannot actually prevent an employer from treating you unfavourably in the first instance. But it if you believe that you have been discriminated against, harassed or victimised on the grounds of being a disabled person, you can bring a legal claim against the employer to a tribunal court. This means that you can seek recompense for being treated unfavourably and the court can even overturn decisions made by an employer, such as an unfair dismissal from a job.

It also means that you can assert your rights under the Act in order to encourage an employer to change how they are treating you. By describing or pointing towards your rights as a disabled person under the Equality Act 2010, you can make it clear to an employer that they have a legal duty towards you.

Many employers are aware that they have a duty under the Act, but may not know exactly how it applies to you in your current circumstances. If you believe that you may be being treated unlawfully and can make your employer aware of your rights and their duties, then you may be able to help change their approach towards you.

# **Bullying at work**

Some working environments are supportive, others are not. The Equality and Human Rights Commission says people with a disability or long-term illness are more than twice as likely to report bullying or harassment in the workplace.

Bullying or harassment is never acceptable and, if you have an illness like M.E., the stress can make your symptoms worse. If you are being bullied, tell someone you trust – even if you are unsure, embarrassed, afraid you're "just being over-sensitive," worried about victimisation or reluctant to get someone in trouble.

ACAS (see useful contacts on p 41) operates a free helpline on employment-related disputes and other issues, including bullying and discrimination in the workplace. A leaflet on bullying can be downloaded from its website and offers advice on what to do if you are thinking about confronting the bully, making a formal complaint and if necessary, taking legal action.

Your staff handbook may have a policy on bullying, which tells you who to speak to. It may be your line manager or, if they are the problem, their manager or your personnel/HR department, staff representative or union representative.

If you are feeling low and need emotional support about bullying or any other issue, contact the Samaritans (see useful contacts on p 41).

# The Health and Safety at Work Act 1974

This piece of legislation essentially requires employers (of any size) to take practical steps to prevent accidents or harm to employees. What exactly is required of an employer will depend on their size and the nature of the business.

This Act, along with the Management of Health and Safety at Work Regulations 1999, places a legal responsibility upon employers to minimise the risk of stress-related illness or injury to employees. This means that work-related stress is viewed seriously in the eyes of the law and that employers are expected to respond appropriately when employees raise issues and concerns relating to feelings of stress or other symptoms which may be exacerbated by stress.

## Rights of carers

Carers have a legal right to take some (unpaid) time off for a dependant who has M.E. (though there are exceptions for some jobs). The Work and Families Act 2006, Employment Rights Act 1996 and Equality Act 2010 support carers' rights to:

- request flexible working (employers have a legal duty to seriously consider requests but are not forced to agree them)
- take a reasonable amount of time off to deal with emergencies and make further arrangements in the case of a dependent person with M.E.
- take a period of parental leave to care for a child or young person with M.E.
- not be treated unfavourably because of their relationship with a person with M.E. (known as discrimination by association).

Action for M.E. (see useful contacts on p 41) can provide information and signposting for carers, including on employment rights.



# Identifying and communicating what you need

Managing fluctuations in M.E. symptoms, and working out what will help you to reliably sustain a job, can be challenging. Communicating this, and negotiating what you need with an employer, may feel daunting. As a result, many people choose not to say anything or leave it to the employer to take the lead.

It can be extremely helpful to take an active, positive approach to working out what you need and to communicating this to your employer, whether you are new or have worked for them for many years. This is because you will want to feel as much in control of the situation as possible, and not just be pulled along by whatever approach your employer takes. This will give your employer more confidence that you can manage yourself well and express what you need in order to become or remain a reliable employee.

## Challenges, needs and solutions

This is a staged, solution-focused approach to considering how your M.E. symptoms affect you at work and what may help you to overcome any difficulties you are experiencing. Using the headings shown in the table on p 10 can help you organise your thoughts and give you a tool to use when discussing this with your employer.

You may not have all or even any of the solutions in mind right now. That's fine: at this stage what is most important is to be able to clearly separate out your challenges and your needs. You can discuss possible solutions with your employer and anyone else that is supporting you. When an employer tells you that a specific solution is not possible, for any reason, go back to your corresponding need and discuss how you can meet it.

Challenges	Needs	Solutions
List the ways in which the symptoms you experience interact with any aspect of your working life.	List what you really need in order to overcome each challenge. Do not list specific solutions to meet the need.	List the ideas or proposals you have for specific solutions which will help to meet your needs.
For example:		
• Commuting in rush hour is exhausting and steals so much energy from my working day.	• I need to better manage how I spend my energy throughout each working day.	<ul> <li>Changing my working hours to avoid rush hour and/or doing some home working.</li> </ul>
<ul> <li>I become fatigued and pained much more quickly from sitting or standing for long periods.</li> </ul>	<ul> <li>I need to reduce time spent on more fatiguing activities or how fatiguing a particular activity is.</li> </ul>	<ul> <li>Reviewing my duties and how I carry them out.</li> <li>Perhaps getting a specialised, more supportive chair.</li> </ul>
• I find keeping up with fast conversations in team meetings difficult due to		<ul> <li>I need to ensure I can keep up, contribute and take clear notes away from team meetings.</li> </ul>
experiencing brain fog.		<ul> <li>Can we discuss this at the next team meeting as some small changes may help me and be useful for others too?</li> </ul>

# Positively managing disclosure

Whether you have just been offered a job or have been working for an employer for some time, considering whether or not to disclose your diagnosis or symptoms or M.E. to an employer can feel like a difficult decision.

There is no absolute right or wrong with disclosure and there is no legislation that says you must. Be aware though that not telling your employer about a health condition which later impacts on your ability to work could, in a worst case scenario, be considered a breach of your contract of employment. This could lead to disciplinary action, including dismissal. However, this is rare and will depend to a great extent on your relationship with your employer.

To help you feel clearer on what you want to say and why, spend some time considering:

- your current health and how well you are managing your symptoms
- the specific challenges of the job or working environment
- whether you are struggling and would benefit from greater awareness and support
- your relationship with your manager (are they likely to be understanding?)
- the policies and procedures that your employer will follow if you do disclose.

#### Who do I tell and when do I tell them?

Consider who you want to disclose to and at what point, so that you benefit from it. You don't want to feel suddenly forced into disclosing when you are not ready, to a person you don't feel comfortable telling.

So consider your situation and the process you are involved in (eg. completing an occupational health assessment form after receiving a new job offer, having a regular one to one meeting with your manager, returning to work after a period off sick) and prepare yourself in advance.

If you do find yourself being asked unexpectedly, consider saying that you are happy to have the conversation but would prefer to arrange a more suitable time and place to do so.

#### How do I tell them?

Keep it short in the first instance so you don't overwhelm them with information. Let them ask questions if they need to. If you are worried about what you will say and how you will feel once you start speaking, then consider writing a brief statement in advance and handing it over.

If you have real concerns about the person you have to tell not being very sympathetic, then consider arranging to bring someone with you to the meeting.

# What do I say?

Have details ready about how your symptoms impact on your ability to get to work and carry out your job. Then focus on the positives and solutions that can be put in place.

- What you are doing to manage your health?
- What will help you to overcome the difficulties you are experiencing at work?
- Offer to provide further information or input from a specialist, such as your M.E. clinician, Access to Work (see p 20) advisor or Health and Disability Work Coach at Jobcentre Plus.



# Reasonable adjustments

Employers have a legal duty under the Equality Act 2010 (see p 5) to make reasonable adjustments to the workplace or working practices so that employees with M.E. are not placed at a disadvantage. While you may not consider yourself to be a disabled person, M.E. is legally recognised as a condition which may give a person rights as such.

Reasonable adjustments can apply to:

- the application and interview process for a job
- where, when and how much you work
- your workplace environment
- your duties, how you carry them out and how your colleagues work with you
- support or equipment to enable you to carry out your job.

If you have been invited to a job interview and are concerned that having M.E. places you at a disadvantage, then you could consider requesting that:

- the interview is held at a location accessible for you, within an environment free from excessive noise or light
- rest breaks be built into longer interview/assessment procedures
- you can use prepared notes to aid your memory.

If you are struggling with your current job or are off sick from work then exploring the following reasonable adjustments with your employer may help:

- flexible hours and time-keeping (see p 14)
- changes to your workload (see p 15)
- changes to your working environment including extra equipment or aids (see p 15)
- changes to ways of working (see p 16).

The challenges, needs and solutions method outlined on p 9-10 can help you to understand what adjustments you may need and find a positive way to discuss it with your manager.

It is best to talk to your employer sooner rather than later, as the earlier such adjustments are made, the easier it could be for you to manage work, and the better your chances of staying in work.

More information on the law and guidance on reasonable adjustments can be found at www.equalityhumanrights.com/your-rights/employment/work-place-adjustments

When considering any reasonable adjustment you should also always find out if they are likely to have any impact upon your salary or other terms and conditions of your employment.

# Flexible hours and working pattern

How can you make the most of your available energy, without setting yourself back by doing too much? Consider how it might help to:

- change your normal working hours to avoid rush-hour travel
- work flexible or reduced hours; every employee has the statutory right to request flexible working after completing 26 weeks (six months) of employment service, but you can also ask before then as a reasonable adjustment
- work from home if possible
- · have a fixed shift, if you do shift-work
- take longer or more frequent breaks away from your desk, computer or workstation
- attend medical appointments during working hours if required.

#### Workload and duties

A balance between work, rest and play is important to help you manage your M.E. in a sustainable way. With your manager, take time to consider any particularly challenging duties as well as your total workload. You may have some duties which you could swap with a colleague on a temporary or permanent basis.

If you are following a pacing or graded activity programme then you may need to incorporate work very carefully into this.

# Changing the working environment

Small modifications to the working environment can make a big difference. Examples might include:

- providing you with a quiet area where you can have rest breaks without being disturbed
- permission to use an allocated parking space near to the entrance of the building
- moving the location of your workstation to be nearer the entrance or other facilities
- altering lighting or other workstation arrangements, if you are sensitive to light or noise.

The Access to Work programme can provide help with identifying and funding useful equipment or aids and with adapting premises to accommodate them (see p 20). This could be things to help you to manage your symptoms (eg. automatic doors to make offices more accessible if you to walk with crutches or use a wheelchair) or work duties (eg. a height-adjustable desk to enable you to sit or stand for alternate periods).

# Changes to ways of working

This is an often overlooked and under-appreciated area of adjustment. You and your employer may be used to doing things in certain ways just because they have always been so. Could you work together to find alternative, more effective ways of working?

This may help to increase how much work you can manage. Such changes may have benefits for other colleagues, too.

You may wish to consider accessing a form of advice or coaching to help you to adapt your ways of working, taking your symptoms into account. An application could be made to Access to Work (see p 20) to fund a number of coaching sessions from an appropriate expert (including someone who has been through a similar experience and process).

### **Review meetings**

It is advisable, when implementing reasonable adjustments, to agree a timetable for review. Regular reviews can help you and your employer to assess how effective the agreed adjustments have been at enabling you to overcome the challenges and barriers you were experiencing, to identify alternative or additional adjustments which may help and to discuss to what extent your workload and hours are sustainable.

If you feel that it would be helpful, consider who else you might want to invite to attend such meetings. This could be a colleague (perhaps one who has experienced similar challenges and successfully overcome them) or one of the additional sources of expertise listed on p 18-20.

# Communication and confidentiality

It is advisable to ensure that key points discussed and agreed with your employer are recorded in writing, so that they can be referred back to later. If you experience cognitive difficulties (such as with concentration or memory) then ask in advance or at the start of any meetings for a written summary to be sent to you afterwards. It is especially important to have a written record of any changes which impact upon your job role, salary or other terms and conditions of your employment.

If no written record is taken in a meeting (eg. because you had an unplanned, informal conversation with your manager), then write your own summary. Ask for confirmation that have understood fully and that your notes are accurate.

Your employer should keep the personal matters you have discussed confidential. The Data Protection Act says employers must ensure confidential and appropriate handling of "sensitive personal data," which includes information about a person's health. This means that information about your M.E. should not be shared with any other person, inside or outside the organisation, without your prior, expressed consent. Your manager may need to raise certain matters with their manager or Human Resources, to seek further advice or guidance.

Maintaining good communication with your colleagues is also important in terms of professionalism and good will. Some adjustments agreed to may mean changes for other colleagues, and may cause confusion or resentment unless they understand why it is happening. Discuss with your manager what needs to be communicated to whom and when. It may be that your manager can use the opportunity to make a very positive example of how they support employees who have a long-term health condition and you may wish to raise wider awareness about M.E.



# Specialist support

You or your employer may wish to seek further advice from relevant experts in workplace health and reasonable adjustments. For examples of how some employers help their staff with M.E., please see Appendix I on p 44.

# Occupational health

Some employers will refer employees to their occupational health provider for advice regarding reasonable adjustments. This may mean attending a telephone or face to face appointment with a health professional who has specific training and experience in health and work matters. They will assess your health and work and how these impact upon each other.

It is advisable to go prepared to the appointment, with any ideas you have about what can help or hinder you (in terms of work and managing your health and recovery). The occupational health professional will usually be asked by your employer to produce a report summarising your condition, their prognosis (likely timescale for your return to work and/or how much work you can tolerate) and their recommended actions, including effective adjustments that they would consider to be reasonable.

Usually you would expect any medical information to be kept confidential between you and your health professional, so employees are usually asked to give signed consent to this information being communicated to their employer.

This might happen at the point of referral to occupational health, or when you first started working for the employer, or it may not have been formally requested at all.

You have a right to see the report before it is sent to your employer, and to request changes to any facts which you believe are incorrect or have been misrepresented (but you do not have a right to request changes to professional opinions that are given). If you would like to do this then make it clear during your Occupational Health appointment.

#### Fit for Work

Fit for Work (see useful contacts on p 41) is a relatively new service which most employers are still not aware of. You or your employer can ask for well-informed and impartial advice, delivered by a team of occupational health professionals.

If you have been off sick from work for more than four weeks (or are likely to be) then your employer or GP can refer you to Fit for Work for a voluntary occupational health assessment.

# Specialist clinician

If you are a patient at a specialist NHS M.E. service, or are seeing another relevant healthcare professional, you may be able to discuss your work-related aspirations and challenges with them. They may be able to write a letter to your employer, including their professional opinion and advice on what will help you to return to or sustain work

# Health and Disability Work Coach (Jobcentre Plus)

Whether or not you are claiming benefits, seeking work or have a job, you can access information and advice through the Disability Employment Advisors (called Health and Disability Work Coaches in some areas) in some (but not all) Jobcentre Plus offices (see useful contacts on p 41).

They have a wealth of knowledge and experience and can refer you to local services for additional support.

#### **Access to Work**

Advice and financial help may be available to you through the government's Access to Work programme (see useful contacts on p 41).

Access to Work provides practical advice and financial support to help overcome the barriers to work experienced by disabled people and people who have long term health conditions. The programme aims to be flexible and responsive to your individual needs and your job.

The support that Access to Work can fund is above and beyond what would be considered a reasonable adjustment and does not replace an employer's legal duty to make them (see p 13). It can fund:

- support workers to assist you with some aspects of your job
- standard equipment, such as an ergonomic chair to promote 'active sitting'
- bespoke equipment, ie. anything built specifically for you and your job
- assistive technology, such as speech recognition software
- training and coaching, eg. to help you adapt to new ways of working or for colleagues to better understand your needs and how to work with you.

You don't need to know exactly what Access to Work might fund for you as the process of applying will determine that, but you do need to make the application yourself. It will be in your name, not your employer's, and many employers do not know about it or do not inform their employees.

After your initial application you will be assigned an advisor who will discuss (usually via a telephone call) your job, your health and your needs arising from these. Often they will arrange for an independent workplace assessment at a convenient time for you and your employer.

The assessor will have a more detailed discussion with you, and write a report including recommendations about what Access to Work could fund to meet your needs. Your advisor will also determine the funding that Access to Work will provide. There is no guarantee that they will agree to fund all the items that have been recommended.

Depending on the size of your employer, Access to Work will set a level of funding for the items to be purchased that they expect your employer to provide themselves. This reflects what Access to Work consider to be a reasonable adjustment in your specific case.

# If you are off sick from work

People with M.E. often feel under pressure to continue working when they first become ill or when their symptoms worsen. Unfortunately, trying to push on through the illness can be counterproductive, potentially causing longer sickness absences and slowing improvement or recovery.

If you are off sick with M.E., you may feel too ill to think about anything else but you must meet your contractual obligations by telling your employer straight away if you are too ill to go to work.

How and when you must tell them is usually described in your contract or staff handbook (in turn, your employer has a duty to record sickness absence, eg. for sick pay purposes).

Many organisations require a phone call directly from the sick person if they are not coming in to work. They may not accept an email or text from you or a call from another person.

If you are off sick from between four days to one week, then you can often complete a form (self-certification) on your return to work so you can get sick pay. If you are off work for longer then you will usually have to get a fit note from your GP (see p 22).

If you do not meet your contractual obligations about contacting your employer and getting a fit note from your GP when required, sick pay may be refused and you may face disciplinary action.

The government is funding an initiative, to support employees, employers and GPs when a person is off sick from work or has a fluctuating long-term health condition, called Fit for Work (see useful contacts on p 41).

#### Fit note

The fit note (or Statement of Fitness for Work) was introduced in place of the doctor's sick note in 2010.

It enables your GP to state if they think you are fit for work, not fit for work or may be fit for work "taking account of the following advice" with space for the GP to add additional suggestions including:

- a phased return to work
- altered hours
- amended duties
- workplace adaptations.

The advice on your fit note is from your GP to you, and your employer is not legally obliged to do what they suggest. However, if your employer does not follow the advice then they should act as if you are considered to be "not fit for work." It may be that your employer wishes you to attend a meeting to discuss your needs, or an occupational health assessment, before they make any firm decision about your return to work.

### Long-term sickness

If you find yourself unable to go to work for a longer period because of your symptoms, then this is considered to be a capability and possibly a disability issue, rather than a disciplinary matter (unless you have not been keeping to your contractual requirements to keep in touch and submit fit notes).

If you are off work long-term, your employer should keep in regular contact, discuss options for returning to work, arrange return-to-work interviews and discuss a programme with you for getting back to work.

Make sure that you ask your employer for copies of any relevant policies and procedures (or a copy of the staff handbook) if you do not have these at home. This way you can be sure you are following them appropriately.

Also make sure that you are clear on your pay and/or sick pay situation. You don't want to feel any added anxiety because you are unsure or believe that you have to return to work (for financial reasons) before you feel ready.

Your employer should carefully consider making reasonable adjustments (see p 13) and support a phased return to work, to help you to continue in work.

If you decide to reduce your hours or change your role, make sure you know the impact this will have on your income and any other terms and conditions of your contract (eg. annual leave or pension contributions).

# Return-to-work planning

While off sick from work and experiencing difficult symptoms, it can be hard to imagine how returning to work could happen. If you are thinking about how it could be best managed or if you have already agreed a date to return, a good return-to-work plan is essential.

A clear, carefully thought out plan that has been agreed by everyone involved will help you and your employer to feel more confident that it can be successful. This is far more preferable than going back to work and hoping it will be okay.

A good return-to-work plan will include consideration of all of the following:

- a phased return-to-work period (see below)
- reasonable adjustments (see p 13)
- Access to Work (see p 20)
- review meetings (see p 16)
- confidentiality and communicating with colleagues (see p 17).

# An M.E.-appropriate phased return to work

A phased return to work is a commonly used approach to supporting employees who have been off sick from work. It is a period over which you build up your working hours, towards your fully contracted number, while receiving your full salary.

Many employers initially propose a period of gradually increasing hours of around six weeks. However, returning to work after a period of absence due to M.E. may require a much more gradual approach in order to be successful and sustainable.

Planning to return to work should be a process of making informed decisions, based upon what is believed will be most likely to succeed, for you as an individual – and not a "one size fits all" policy.

It will be helpful to discuss your phased return with your specialist M.E. clinician, occupational health provider or GP, particularly if you are following a pacing or graded activity plan.

If the maximum phased return period that your employer can offer is not suitable for you, then you can try to extend the total period by using some of your annual leave to reduce your hours over number of additional weeks. In addition, you could consider requesting a temporary reduction in your contracted hours for a further number of weeks.

While this will mean reduced income for you, it might help to extend the total return-to-work period to a manageable length. In the end, you are trying to plan for success, rather than take risks, and it is success in the longer term that may be more important to you and your employer.

It is important to plan in some flexibility to make allowances for setbacks or relapses. You might expect to find it challenging and that some of your symptoms may feel worse to some extent, for some of the time. For some people this will be an important sign to stop. But you may find this tolerable and it may get easier over time. It is good to remember this so that you do not panic and stop just as soon as you experience any increase in symptoms.

In the end, nobody knows you better than you know yourself and everyone's situation is unique. You can take advice from all sorts of directions, but you need to be in control of your own plan, how fast you increase your hours, and if and when you should stop. Action for M.E. (see useful contacts on p 41) has information and advice on pacing, to help you manage your energy levels in and out of work.

Within a phased return period, you and your employer should also consider:

- building up work or work-related skills at home at first
- planning in some home-working days once you have started to return to the workplace (to reduce the amount of energy you spend on commuting)
- building up your workload or targets as well as your hours (giving you a good chance to build up your confidence first, which then help you as your hours increase)
- allowing for regular breaks and perhaps a longer lunch so that you can rest.

# If working isn't working: leaving work well

If it becomes apparent that your health is not getting any better, or that your employer is unwilling or unable to support you, you need to take stock. There are a number of steps to consider, depending on your specific situation, how far from being able to return to work you are and how far communications have broken down.

## Career break or unpaid leave

Some, mostly larger, employers will have a policy allowing employees to request a longer period of unpaid leave from work (up to 12 months in some cases). It is worth asking if you can apply for this, as it might just give you the time you need to focus on managing your health and allow your employer the opportunity to recruit someone to cover your job for the period.

#### **Contract variations**

Might you be able to request a temporary or permanent variation to your contract, to reduce the number of hours you have to work? While this will reduce your income, it might be a way of retaining your employment. Your employer may be able to recruit someone to work part-time and job-share with you, to ensure that the work gets done and they can still keep you employed.



# If your employer is being unsupportive

If your line manager is not really trying to understand and/or is not willing to make any changes to help you to keep your job, it might be possible to involve another manager, your human resources department and/or a union representative (if you have one) to help move things forwards more positively.

In this kind of situation it is advisable to keep a record of any discussions, meetings, emails, letters or other communications and actions you take to try to remedy the situation. You may need to refer to these or use them as evidence later.

If you feel stressed and at risk of losing your job, then you may need to consider making a formal internal complaint. This is known as raising a grievance (see p 28).

Alternatively or in addition to this, you may wish to involve some external expertise or support. This could include trying mediation to help resolve differences and agree a way forward. See useful contacts on p 41 for:

- Disability Employment Adviser/Health & Disability Work Coach at Jobcentre Plus
- ACAS (for England, Scotland and Wales)
- Labour Relations Agency (for Northern Ireland)
- Citizens Advice Bureau.

# If you lose your job (or are about to)

If your employer has acted fairly, has done their best to understand and support you through making reasonable adjustments (see p 13) and it is still not feasible for you to continue in work, they may lawfully dismiss you on grounds of capability (ie. because you are no longer capable of doing the job you are contracted to do).

If you lose your job, or are about to, speak to an experienced adviser, such as ACAS, your local Citizens Advice Bureau or Jobcentre Plus office, as soon as possible (see useful contacts on p 41). They can advise you about whether your employer has acted reasonably and tell you about welfare benefits.

If you are advised that your employer has not acted fairly and made reasonable adjustments, you may have grounds to take your employer to an employment tribunal for disability discrimination.

If you give up your job because your employer has put you under unreasonable pressure, you may have grounds for a claim for what is legally known as constructive dismissal. It is essential to get experienced advice from one of the agencies listed above right away, because any claim you wish to make to an employment tribunal must be made within three months of the date of your dismissal

Ideally, to the best of your ability and as far as your employer has allowed, you will want to leave with the best possible relationship with your former employer. In the future you may wish to try to seek work with them again or ask them to provide a reference for you. If you are taking legal action against them it may be possible to seek a legally binding agreement regarding your reference.

# Coping with job loss

Losing your job can be stressful. It can affect not only your income but your self-confidence, daily routine, sense of purpose and even your social life. Feeling angry, hurt, rejected and/or anxious is natural. You may even find yourself grieving for what was. If you feel like this, don't bottle things up.

Reach out for support: the Samaritans are there to listen 24 hours a day (see useful contacts on p 41).

If you are furious at your former employer, you could try getting it out of your system by writing down everything you wish you could say to them, but don't post it – you never know when something written in anger may have consequences later.

Give yourself time to come to terms with what has happened. Right now, this might seem like the end of the world but you will get through it.

### Grievance procedure

If speaking to your manager and others doesn't work, you may wish to consider formally submitting a grievance using your company's standard grievance procedure. This is usually described in a staff handbook or in a separate policy and procedure document.

Many people feel anxious about raising a formal grievance, due to concerns over the consequences. It may be possible to seek confidential advice internally from human resources or another manager, if available. Or you can contact ACAS or the Labour Relations Agency (see useful contacts on p 41).

You may be required to have raised the issue in this way if you later take legal action against your employer, as they will want to be assured that all internal procedures have at least been attempted in the first instance.

#### Mediation

Will your employer agree to try mediation through ACAS (in England, Scotland and Wales), the Labour Relations Agency (in Northern Ireland) or a local mediation agency to try to reach an amicable solution?

These organisations have specialists who can meet with you and your employer together, to impartially try to help you to reach an agreeable resolution to any problems.

# Legal action

If your employer has failed to meet the requirements of the Equality Act 2010 (see p 5) and you do not reach an agreement through mediation, you could take your employer to an employment tribunal and claim disability discrimination. Employment tribunals are independent judicial bodies which consider disputes about employment rights (including dismissal, redundancy and discrimination).

The Employment Tribunals Service says you have grounds to go to tribunal if you have "suffered a detriment, discrimination including indirect discrimination, and discrimination based on association or perception, harassment or victimisation and/or dismissal on grounds of disability or failure of employer to make reasonable adjustments."

Going to an employment tribunal is not an easy option and we suggest that you first seek advice from ACAS, Citizens Advice and/or your trade union if you are a member (see useful contacts on p 41).

It is now a requirement that you notify ACAS if you want to take a claim to an employment tribunal. ACAS will offer a free and confidential process of early conciliation in advance of your claim being accepted by the court, but this does not force you or your employer to take part in the process.

It is important to get experienced advice as soon as possible, as a claim to an employment tribunal must be made within three months of dismissal or the act of reported discrimination. There is an "issue fee" (currently £250) to be paid to start your claim to a tribunal court and a "hearing fee" (currently £950) for the claim to be heard in court.

If you are on a low income or certain qualifying benefits then you may qualify for fee remission (ie. reduced or waived fees).

# If you are aspiring to work in the future

Managing your symptoms and aspiring to work in the future can seem daunting. Feeling worried about being able to attend and perform reliably at work is understandable, as are concerns about competing for a job and wondering whether an employer or new colleagues will be understanding and supportive of your needs.

Taking a planned and supported approach towards employment can be rewarding and successful. Many people with M.E. are able to find their own unique way into work which is satisfying and can be managed throughout periods of fluctuating symptoms.

# Planning and support

Any good plan includes flexibility, and it's only natural that difficulties and setbacks may arise along the way. You might wish to decide on a preferred "direction of travel" towards work, rather than an absolute goal that you feel you must achieve. You can plan for what you will do if you meet obstacles that you feel you cannot overcome.

Family and friends can be your closest and most important allies, but can also raise worries on your behalf out of concern for your wellbeing. You may want to consider how you can tell them about your work aspirations in a way which acknowledges their concerns, while making it clear that you are asking for their support to overcome challenges along the way.

It could help to tell your GP or specialist clinician about your work aspirations, and spend some time planning strategies to support any new activities, plus how you might respond if symptoms worsen.

The experiences of others who have tackled similar issues can provide you with helpful insights. Could you speak to other people with M.E. who understand your situation? Action for M.E. (see useful contacts on p 41) has a searchable services directory to help you find an M.E. support group in your area, and a peer-support forum, M.E. Friends Online.

While most widely available employment services are focused on assisting people who are actively seeking paid work, it can be helpful to find out where your local services are and what they do. Some will be able to provide useful information and advice when planning and taking first steps, as well as enabling you to feel a step closer to accessing their services when the time is right.

You can find out more by speaking with a Health and Disability Work Coach at your local Jobcentre Plus or contacting the National Careers Service (see useful contacts on p 41).

### Volunteering

Finding a voluntary activity which interests and motivates you, and can be done at your own pace and at the times to suit you, can be a great starting point. There is a vast range of volunteering opportunities available which can provide you with the chance to:

- · do something which brings a sense of achievement
- gain confidence
- build up your activity levels gradually over time
- manage your energy and symptoms within your pacing programme and discover strategies may help you manage your pacing when you are in the workplace
- develop or refresh your skills and experience
- add new things to your CV and improve your job prospects
- meet new people and network for future work opportunities.

Volunteering will usually not affect your welfare benefits claim, but it is always worth checking this with an adviser at your local Jobcentre Plus.

Information and support for those considering volunteering can be found via a local volunteer centre. Lists of centres and opportunities can be found online at www.do-it.org.uk

## **Training and education**

You may wish to consider starting by attending a short or part-time course to learn something new, refresh a skill or start to build up your activity. In addition to traditional learning opportunities there are now also many online courses and community computer centres (such as libraries) at which you can study if you do not have a computer at home.

If you are considering training or education options to help you to pursue your future employment aspirations, then the National Careers Service (see useful contacts on p 41) is a good place to start.



# Looking for work

When you are ready to look for work there are a number of sources of job vacancies. Your local paper, Jobcentre Plus (see useful contacts on p 41) and online job sites are all good starting points. These could include the government's Universal Job Match database (www.jobsearch.direct.gov. uk) or commercial recruitment websites. Trade magazines and professional journals are often used to advertise job vacancies in specific occupational sectors.

Make sure that any commercial websites you use are reputable and you have read the terms and conditions before subscribing and uploading any personal details.

Only around 40% of jobs are advertised. The others are filled by word of mouth and networking through informal and/or professional networks (eg. LinkedIn). Talk to people you know about where they work; ask if there are any jobs going and what their organisation is like as an employer. When you are returning to work after a period of recovery from M.E. it is essential to know that any potential employer is flexible and promotes a positive work environment.

# Applying for work

Applying for a job is a challenge, whoever you are. A good application takes time and thought and most people are nervous in an interview situation.

The key to an effective job search is to target your applications effectively and make sure that you can show the employer that you have the skills and experience they are asking for by giving examples from your working life.

It is also essential not to make assumptions about what an employer is thinking. A job that is advertised as full-time may be possible as a part-time job, job-share or flexible working.

The National Careers Service (see useful contacts on p 41) offers practical advice on networking and other aspects of applying for work including building your CV, application forms, covering letters and interview techniques. There is also information about courses, funding and routes into different careers.

If you are considering a career change, there are a number of online tools that can help you explore your skills and interests – try the National Careers Service skills heath check or talk to a one of their advisors.

### **Understanding employers**

When you have M.E. it can be difficult to imagine returning to the same kind of work that you have done in the past. However, when you have the strategies in place that help you manage your symptoms, you may find that it is possible with a sympathetic employer, reasonable adjustments and the other support discussed earlier in this booklet.

It also always worth doing your research on employers you are applying for a job with, or specific employers in your local area. Consider whether they have a reputation for being a good employer or if they have any industry or national awards that show that they are likely to be. The government's One Tick (Equal Opportunities Employer) and Two Ticks (Positive About Disabled People) schemes are awarded to employers who can demonstrate good practices when it comes to recruiting and supporting employees who are disabled or have a long-term health condition. The government is also currently running a campaign (Disability Confident) to help advise and encourage more employers to recruit more disabled people, and more and more organisations and companies have signed up to this.

# **Employers and health-related questions**

In most cases, employers are not allowed to ask job applicants about their health or any disability, including questions about previous sickness absence, until the person has been offered a job. This includes conditional job offers or an offer of employment for when a job becomes available.

There are exceptions, if asking about your health is necessary to help your employer:

- decide whether you can carry out an essential function of the post
- identify reasonable adjustments to the selection process
- monitor diversity
- take positive action to assist disabled people.

You can complain to the Equality Advisory and Support Service if you think an employer is asking questions unlawfully, or seek advice from your local Law Centre (see useful contacts on p 41).

If you are disabled and you are asked health-related questions during the recruitment process and are not then offered the job, you can bring a claim of discrimination against the employer. The burden of proof that no discrimination took place will fall on them.

# Offers of employment

Offers of employment are often conditional on specific things, such as the employer receiving satisfactory references for you. These conditions should be stated in writing in a letter to you from the employer. It may also include a medical assessment and successful completion of a probationary period (these must apply to all new employees and not just those who disclose a health condition).

If you do decide to disclose your M.E. (see p 11) once you have been offered a job, then you will have a chance to discuss what you may need.

# Sources of support into work

As well as JobCentre Plus and the National Careers Service, there are specialist agencies which help people with disabilities and long-term health conditions into work. Work Choice and the Work Programme (see useful contacts on p 41) can advise you and support you to access any specialist charities or agencies offering services in your area.

Work Choice is a national programme intended for people with needs relating to long-term health conditions or impairments whose needs cannot be met through other widely available schemes.

Work Programme is the main work support scheme for claimants of Jobseekers Allowance or Employment and Support Allowance, and most services delivering the Work Programme will have Work Coaches who specialise in supporting disabled people and people with long-term health conditions.

Through Work Choice and the Work Programme you can be trained, advised and supported to apply for jobs, attend interviews, gain work experience/do a work placement, take courses, disclose information about your health and negotiate for reasonable adjustments (see p 20) once you have been offered a job.

At the time of writing the UK Government is designing a new Health and Work Programme which will replace Work Choice and the Work Programme across the country.



# Money matters

Here we outline some considerations, provide a little information and signpost to expert advice about:

- statutory and/or contractual sick pay (see below)
- welfare benefits (see p 38)
- ill-health and payment protection insurance (see p 39)
- ill-health retirement (see p 40).

If you are experiencing problems with specific or general financial issues, please seek advice as early as you can to stop the situation worsening. The National Debtline (see useful contacts on p 41) can offer information and advice.

# Statutory Sick Pay (SSP)

You may be entitled to SSP as long as you have been earning at least the "lower earnings limit."

SSP is paid to you by your employer for up to 28 weeks in any period of sickness lasting for four or more days. It is primarily the employer's responsibility and the scheme is operated by HM Revenue and Customs. For this reason, your employer must keep accurate sickness absence records on employees.

Normally you cannot get SSP for the first three days that you are off sick and you only become eligible from the fourth day.

If you are still sick at the start of the 23rd week of entitlement to SSP your employer will need to complete and send form SSP1 to you. If your employer stops paying your SSP for any other reason they will also need to complete and send you the SSP1 form. This form will allow you to claim state benefits.

You may be entitled to certain welfare benefits whilst on SSP.

## Contractual sick pay

Depending on the terms of the employment contract your employer operates, you may be entitled to contractual sick pay in addition to SSP, or when SSP is not payable (for example, after 28 weeks of sickness).

You may also be entitled to make an application for welfare benefits or payment under any permanent health insurance schemes that you have, either privately or through an employer.

#### Welfare benefits

If you are receiving SSP you may also be entitled to other benefits. This will depend on your (and your partner's) personal circumstances.

Employment and Support Allowance (ESA) is the main benefit that is currently claimed by people who are incapable of work due to ill health. ESA is mostly claimed by people who do not have a job and are considered to have no or limited capability for work. It is also possible to claim ESA when you are employed but are off sick from work and are not or no longer entitled to claim SSP.

There are two types of ESA, as follows:

- contribution-based ESA is not means-tested but if you get an ill-health retirement pension or permanent health insurance this may affect the amount you can claim. Contribution-based ESA is based on you having paid sufficient National Insurance contributions in certain years before you claim.
- Income-related ESA is means-tested and entitlement to this will take into account you and your partner's earnings, savings and capital.

It is possible to receive contribution-based ESA and income-related ESA at the same time. You may also be able to get help with your mortgage interest payments through income-related ESA. There is a waiting period before you can get this help, however.

If you are working but have low-salaried earnings then you may be entitled to claim Working Tax Credit to top up your income. ESA, Working Tax Credit and Jobseekers Allowance are currently being phased out to be replaced by Universal Credit. This is a single monthly payment for people who are in or out of work, which merges together these current benefits and tax credits.

In addition, whether you are in work or not, you may be eligible to receive Personal Independence Payment (PIP), which has replaced Disability Living Allowance for people of working age. PIP is a non-means tested benefit that is designed to help with the extra costs of living with a long-term health condition or disability.

It is best to get a complete benefit check done to ensure that you are getting everything to which you are entitled. Action for M.E.'s Welfare Advice & Support Service (see useful contacts on p 41) can give information and advice on welfare benefits.

#### Ill-health insurance

Some people with M.E. have insurance or a pension scheme which pays an income if they are unable to work because of long-term illness. This may be taken out independently or as part of a scheme through your employer.

Check your personal and employer-run policies to find out your options.

# Permanent health or income protection insurance

Permanent health insurance (PHI) or income protection insurance pays a fixed income if you are unable to work long-term because of accident or ill health.

If you make a successful claim, you can remain off sick from work but still employed, whilst receiving an income from the insurance for a set period or until you return to work or retire (depending on your policy).

You may not be able to make a claim for an illness you already have or have had before and some illnesses may be exempt from some policies.

Citizens Advice and the Money Advice Service (see useful contacts on p 41) warn that, if your claim is successful, you will not receive your full income from PHI, and you will have to wait some time before payments start.

#### Ill-health retirement

Alternatively or in addition to PHI, you may belong to a pension scheme that allows you to retire due to ill health and claim your pension earlier than your planned retirement age.

The pension provider will require formal medical evidence to be submitted, which clarifies the effect of your health condition/symptoms upon your ability to carry out your job. You may be required to attend a medical assessment with a representative of the pension provider, or the evidence might be submitted by your employer's occupational health provider. In either case they may request further evidence to be submitted by your GP and/or your specialist M.E. clinician.

If you want to retire and your claim is successful, then the amount you receive will usually be less than the full pension you would have got at retirement age and you may not necessarily receive a lump sum. The ill-health retirement payment of many pension schemes will be made at one of two or three tiers.

Essentially these relate to decisions upon:

- how long it has been determined that you are unable to work for
- whether it is just your current job or all work that you are unable to do.

You will need to check your pension scheme details and can seek advice and support through the Pensions Advisory Service or Citizens Advice (see useful contacts on p 41).

# Useful contacts (in alphabetical order)

#### **ACAS**

Information and advice on employment-related disputes and other issues in England, Scotland and Wales

Tel: 0300 123 1100

www.acas.org.uk

#### **Access to Work**

Employment support programme that aims to help more disabled people start or stay in work

Tel: 0345 268 8489

Email: atwosu.london@dwp.gsi.gov.uk

www.gov.uk/access-to-work

#### Action for M.E.

For information about M.E., including booklets and factsheets

Tel: 0117 927 9551

Email: admin@actionforme.org.uk

www.actionforme.org.uk

#### Action for M.E. Welfare Advice & Support Service

For specialist information and advice regarding welfare benefits

Tel: 0800 138 6544 (call for opening times)

Email: welfare@actionforme.org.uk

#### Citizens Advice

Free, independent, confidential and impartial advice

England: 0344 411 1444. www.citizensadvice.org.uk

Wales: 0344 477 2020. www.citizensadvice.org.uk

Scotland: 0345 404 0506. www.cas.org.uk

Northern Ireland: www.citizensadvice.co.uk

#### **Equality Advisory and Support Service**

For issues relating to equality and human rights in England, Scotland and Wales

Tel: 0808 800 0082

www.equalityadvisoryservice.com

#### Fit for Work

A free, impartial government-funded initiative designed to support people in work with health conditions and to help them, their employer or GP with sickness absence

Tel: 0800 032 6235

www.fitforwork.org

#### **Jobcentre Plus**

Can help to put you in touch with a Disability Employment Adviser

Tel: 0345 604 3719

www.gov.uk/contact-jobcentre-plus

#### **Labour Relations Agency (NI)**

Information and advice on employment-related disputes in Northern Ireland

Tel: 028 9032 1442

www.lra.org.uk

#### **Law Centre**

Law Centres defend the legal rights of people who cannot afford a lawyer

England, Wales and Northern Ireland www.lawcentres.org.uk

Scotland www.scotlawcentres.blogspot.co.uk

#### **Money Advice Service**

Free and impartial advice about debt and financial matters

Tel: 0300 500 5000

www.moneyadviceservice.org.uk

#### **National Careers Service**

Advice and information on a wide range of jobs, training course resources and funding

Tel: 0800 100 900

www.nationalcareersservice.direct.gov.uk

#### **National Debtline**

Free help and advice on dealing with your debt in England and Wales

Tel: 0808 808 4000

www.nationaldebtline.org

#### Office for Disability Issues

Information and advice about the Equality Act and other relevant legislation

Tel: 020 7340 4000

Email: office-for-disability-issues@dwp.gsi.gov.uk

#### **Pensions Advisory Service**

Provides free information, advice and guidance on pension schemes

Tel: 0300 123 1047

www.pensionsadvisoryservice.org.uk

#### **Samaritans**

Confidential emotional support, 24 hours a day

Tel: 116 123

www.samaritans.org

# Appendix I: How some employers help their staff

This chapter includes accounts by a variety of employees with M.E.

If you are an employer who has supported someone with M.E., or an employee who has benefitted from such support, please tell Action for M.E. (see useful contacts on p 41) so that we can highlight this good practice.

#### Sarah's story

"I was very lucky that the occupational health staff in my place of work were very helpful and understanding, as was my line manager. I wasn't put under any pressure to return to work and in fact my manager thought it might be better for me to take some more time off to ensure I was absolutely ready to come back – but work had been such a big part of my life that I was finding it difficult and demoralising being off sick for so long, and I was very motivated to go back. Occupational health and my manager liaised with me to create a phased return plan, and I went back to work starting at three hours a day, four days a week "

### David's story

"My employer has been completely supportive and understanding. Without that I would not have made the recovery that I have so far. I receive incapacity benefit and an insurance payment from my firm's disability policy, which has enabled me to very gradually, over the past two years, work a little for them unpaid, flexibly, in order to slowly enable me to return to work. For the first year I worked a few hours from home each week, and this has built up over time."

#### Elaine's story

"I was able to apply for Personal Independence Payment and recently heard that my application was successful. This entitles me to a Blue Badge and enables me to park nearer to work. I also now have access to a small amount of money to help with some of the day-to-day things that I need to help manage my condition. I know I need to continue to make adjustments at work and at home. Before, I was in denial and this wasn't helping my work situation."

#### Jane and Sylvia's story

Sylvia's manager, Jane, reflected that "Sylvia's fluctuating attendance creates high stress levels for her colleagues and the team's relationship was beginning to break down under the strain." Jane was able to arrange for a specialist in M.E. to deliver a short training session for relevant staff, which Jane said was "very positive for her colleagues' understanding of Sylvia's situation and resulted in an improvement in relations."

#### Sam's story

"I was pleased to hear the human resources representative talk about the value of my 15 years' service and how they wanted to retain me, my skills and my experience. I felt really supported and didn't feel alone with it anymore. I decided to submit a request for a period of unpaid leave in order to help get on top of and learn to manage my condition. With help I put together a case to my employer who agreed to a 12-month unpaid absence."

#### A receptionist's story

(This employee asked to remain anonymous)

"I was lucky to be working for a GP practice when I become ill six years ago. I had to take six months off initially. I then started back on the basis of 'Come in when you are able and stay for as long as you can manage.' This usually worked out at one to two hours in the beginning, with relapses, then building over the next six months to four to five hours every day. I soon realised that I would have to cut back permanently. I now work 20 hours over four days."

#### Suzanne's story

"I have been able to work throughout my illness to various degrees thanks to my employer letting me work out the schedule that is best for me. They told me when I first became ill that I needed to do whatever was necessary to get well. I've been given complete freedom to work out how many hours I can work, which changes as my illness changes.

"The nature of my job has also changed as my illness has progressed. At my worst, I found dealing with people outside my team difficult and my internal role was expanded because I found this easier. They allowed me to experiment with various ways of flexible working. For a while, I worked at home for a few hours each day before going into the office. However, I've found that it is best if I work for four days in the office and one day in the middle of the week at home.

"Having somewhere to lie down at work has been very important and space has always been made available for me to do this. Even during the worse stages of my illness, my employer has always made me feel that I was still a valuable member of the team. I have found the support from management and my work mates to be extremely valuable 'therapy'."

#### Michelle's story

"When I got ill I was lucky enough to be working for a multinational oil company. Being a valued member of the team meant that they invested time and money into helping me obtain a diagnosis and sent me to see two experts in the field. The company doctor was extremely supportive and did a good job of explaining my condition to my immediate supervisors. As a result, they tried to help me return to full-time employment by reducing my working hours and giving me low-stress items to work on."

# **Acknowledgements**

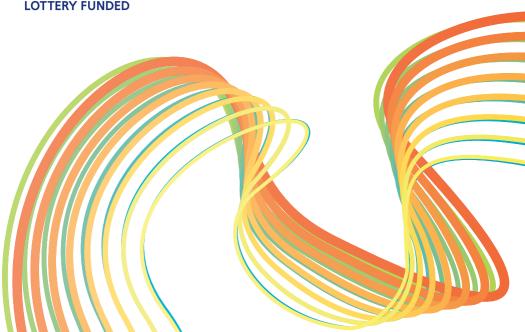
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Action for M.E. takes action to end the ignorance, injustice and neglect experienced by people with M.E. We provide information, support and advice to people affected by M.E. to help improve their health and well-being. We work with professionals to enhance the care and support that people with M.E. receive, and invest in and drive research to advance knowledge of the illness.



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