



# An employer's guide to M.E.



Myalgic Encephalomyelitis or Encephalopathy (M.E.)  
is also diagnosed as Chronic Fatigue Syndrome (CFS)  
or Post Viral Fatigue Syndrome (PVFS).

Transforming the world of M.E.



# Foreword

When a member of staff has a long term illness, or is a carer, you need to understand the condition which affects their lives and the duty you have towards them.

A valuable employee is worth supporting. They know their job. Replacing them would be costly and time-consuming.

Although M.E. is a complex fluctuating condition, many people are able to manage their symptoms and successfully continue with or resume employment. Those who do, show increased loyalty and dedication to their work.

They just need your support.

This guide has been produced with help from people with M.E., Nikie Catchpool, Joint Speciality Lead and Occupational Therapist, Bath and Wiltshire CFS/ME Service, Emma Ife, an employment specialist at Allen & Overy LLP and the HR Dept Ltd.

**"I really value my employer and my boss in particular for thinking I'm worth the effort." Lois**

**"I have – thankfully – managed to stay in work. I have been very lucky to have a supportive line manager, who has helped me a great deal." Lesley**



# Contents

---

Who are we?	4
-------------	---

---

What is M.E.?	4
---------------	---

---

Symptoms and their effects on work	5
------------------------------------	---

---

Your legal responsibilities	7
Equality Act 2010	8
NHS guidelines	9
CIPD guidance	10
Reasonable adjustments	10, 12

---

Sickness absence	16
M.E.-appropriate phased return to work	16
Sick pay	17
Welfare benefits	18

---

Recruiting someone who has M.E.	19
---------------------------------	----

---

Rights of carers	20
------------------	----

---

How other employers help their staff	21
--------------------------------------	----

---

Useful contacts	26
-----------------	----

# Who are we?

Action for M.E. is the UK's leading charity working to improve the lives of people with M.E.

We provide information and support to people affected by M.E. and their carers and campaign for more research, better treatments and better services for them.

You can order our booklets and factsheets from our general enquiries line (see p 26) or download them for free from our Online M.E. Centre at [www.actionforme.org.uk](http://www.actionforme.org.uk)

We also have a Welfare Rights Line (see p 26) for information and advice on welfare benefits, disability discrimination, employment and insurance issues.

# What is M.E.?

It is thought that around 250,000 men, women and children in the UK have M.E., although it is most common in women aged 25-50.

There is a strong possibility that someone you know is affected by the illness. If you work in a large organisation, 1 in 250 members of staff is likely to have M.E.

M.E. is defined as a neurological illness by the World Health Organisation. NHS guidelines say the symptoms can be as disabling as multiple sclerosis, lupus, rheumatoid arthritis or congestive heart failure. However, levels of severity vary from mild and functioning to housebound or bedbound.

As M.E. is a fluctuating illness, symptoms also vary day-to-day.

This booklet outlines symptoms and their affects on work, treatment and causes. More information is available in our booklet, *All about M.E.* or online at [www.actionforme.org.uk](http://www.actionforme.org.uk)

# Symptoms and their effects on work

Symptoms may include persistent exhaustion ('fatigue'), pain, sleep disturbance, 'flu-like symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration.

## Fatigue

M.E. fatigue feels very different from ordinary tiredness. Simple physical and/or mental activities can leave a person with M.E. feeling shattered and struggling to function with the increase in their other symptoms. The impact may be felt straightaway or take a day or two to take affect.

## Pain

Pain may manifest as aching muscles or joints, nerve pains or pins and needles, headache or migraine, twitching muscles or cramps. There may be abdominal pain, stomach or bowel problems.

## Cognitive difficulties

Cognitive difficulties may include reduced attention span, short-term memory problems, word-finding difficulties, inability to plan or organise thoughts or loss of concentration – often described by people with M.E. as 'brain fog.'

## Other symptoms

The illness may affect mood and people with M.E. can also experience poor temperature control, loss of balance, dizziness on standing up, hyper-sensitivity to light, sound, odours, certain foods, some medications, alcohol and other substances.

The fluctuating nature of M.E. can make it difficult for someone with the illness to maintain a consistent level of working. A task that is easily manageable one day may prove impossible the next.

Even when a person's condition appears to have stabilised, it is common for people with M.E. to experience relapses or setbacks, when their health deteriorates again for a period of time. This may happen if they have been pushing themselves too hard.

This is difficult and frustrating for both the individual and their employer.

Understanding more about M.E. and the importance of energy management through pacing (see below) will help you make reasonable adjustments (see pp 10, 12-13) and provide support in the workplace (p 14).

Action for M.E. can supply more detailed information about M.E. and pacing. Call 0845 123 2380 or go to our website [www.actionforme.org.uk](http://www.actionforme.org.uk)

## What causes M.E.?

We don't fully understand what causes the illness. Men, women and children of all ages and all social and ethnic backgrounds can get it.

There is evidence that certain infections can trigger M.E. Many are viruses eg. Epstein-Barr virus (EBV) or glandular fever but M.E. can be triggered by other types of infection and other factors too (further details at [www.actionforme.org.uk](http://www.actionforme.org.uk)).

Genetics may also play a part. M.E. sometimes affects more than one family member.

The youngest person in the UK diagnosed with CFS/M.E. first became ill aged two.

## Treatment

There is as yet no cure for M.E. Treatment consists of symptom management and coping strategies, eg. medication for pain and following a programme such as pacing for energy management.

Some areas have NHS clinics which offer cognitive behaviour therapy and/or graded exercise activity. These therapies should be supervised by practitioners trained in CFS/M.E.

## Pacing

Pacing involves:

- taking short, regular rest periods throughout the day
- identifying activities which use energy (physical, mental or emotional)
- establishing a sustainable baseline for each activity
- once the baseline is established, increasing that activity by no more than 10%, until a new sustainable baseline is achieved.

For further information call 0845 123 2380 or go to [www.actionforme.org.uk](http://www.actionforme.org.uk)

# Your legal responsibilities

Your legal responsibilities to an employee with M.E. include the standard obligations under an employee's contract of employment – plus the additional responsibilities towards people with long-term fluctuating conditions who are now likely to be covered by the Equality Act 2010 if the other tests of disability are met.

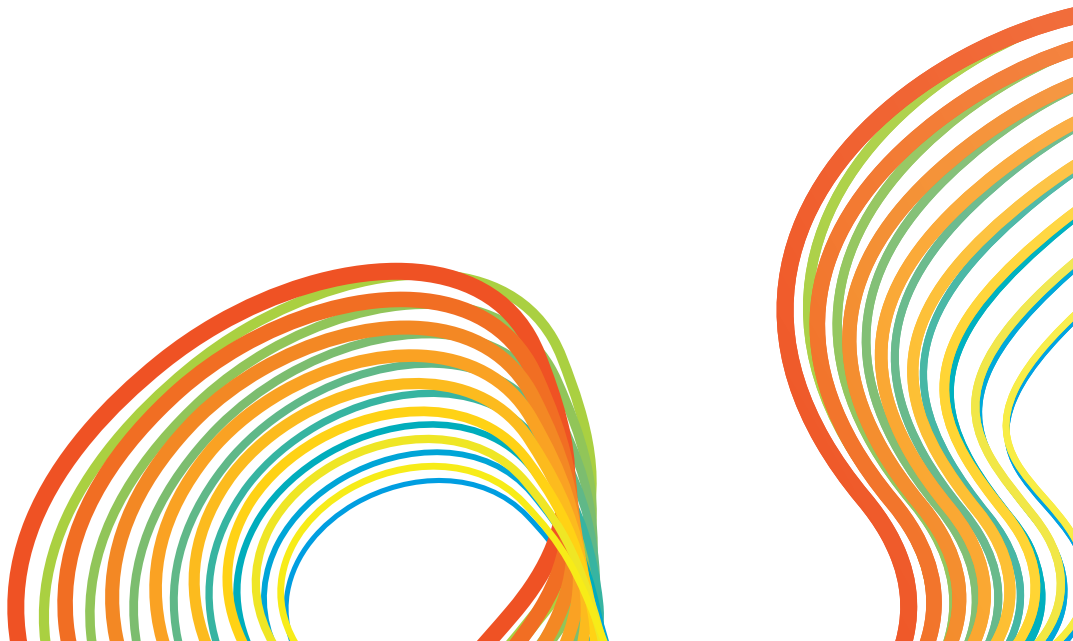
The Equality Act incorporates and builds upon the Disability Discrimination Act 1995 and nine other pieces of equality legislation.

It is unlawful to treat someone less favourably than you would others because that person has a disability. You are obliged to make reasonable adjustments for such an employee or potential employee, or you may be liable under anti-discrimination legislation.

The Health and Safety Executive website (p 26) has a useful page on the law and disability, which includes information on avoiding discrimination, making reasonable adjustments and respecting confidentiality.

**Please note:** This booklet and our website are offered as a general guide and do not constitute an authoritative description of the law, nor should they replace professional legal advice.

***"I am lucky that I am able to work at my own pace and allow rest periods."***  
Nicholas



## Equality Act 2010

This Act has replaced the Disability Discrimination Act 1995 and other equality legislation.

It covers the same groups that were protected previously on the grounds of disability, age, gender reassignment, race, religion or belief, sex, sexual orientation, marriage/civil partnership and pregnancy/maternity – but it changes and extends the responsibilities of employers in some respects.

The Equality Act defines disability as: “a physical or mental impairment that has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.” ‘Substantial’ means more than minor or trivial. ‘Impairment’ may cover, for example, long-term medical conditions and fluctuating or progressive conditions.

M.E. is a long-term fluctuating condition which in most cases has a substantial and long-term adverse effect on the ability of an employee to carry out normal day-to-day activities.

## Your obligations

Most employers already have staff who are covered by the Act, whether you realise it or not, or the employee thinks of themselves as disabled or not.

The Advisory, Conciliation and Arbitration Service (ACAS) has a useful quick start guide to the Equality Act for employers which says the Act:

- puts a duty on employers to make reasonable adjustments to help staff overcome disadvantage resulting from an impairment
- states that it is discrimination to treat a disabled person unfavourably because of something connected with their disability
- makes indirect discrimination applicable to disabled people eg. a job applicant or employee could claim that a particular rule or requirement an employer has in place disadvantages people with the same disability
- makes it unlawful, except in certain circumstances, for employers to ask about a job candidate’s health before offering them work.

**“I went jobshare when I was diagnosed with M.E aged 27. The local authority was very supportive. I was later redeployed.” Paula**



The Act brings in new responsibilities, in addition to existing ones.

It introduces a new protection, described by ACAS as, “the concept of discrimination arising from disability, if a disabled person is treated unfavourably because of something arising in consequence of their disability.”

Disabled people are also protected from discrimination by perception and with regards to rules or policies that apply to everyone but which disadvantage a person with a disability.

Employers are potentially liable for harassment of disabled staff by people they don't employ. The carers of a disabled person are also now protected from discrimination by association.

Employees can now complain about behaviour they find offensive even if it is not directed at them.

They can also claim victimisation if they are treated badly because they have made or supported a complaint or grievance under the Act.

## NHS guidelines

NHS Plus published *Occupational aspects of the management of chronic fatigue syndrome: a national guideline* and *Occupational aspects of chronic fatigue syndrome/myalgic encephalomyelitis: evidence-based guidance for employers*, in October 2006.

Their leaflet for employers says: “Most people with CFS/M.E. are likely to fall under the remit of the Disability Discrimination Act 1995 (now contained in the Equality Act 2010), where there is a requirement to make reasonable adjustments. These may include measures such as: changing locations of work, working from home, modifying work hours, reducing workloads, reducing physical tasks, making provision for a wheelchair, flexibility in working patterns.”

In 2007, the National Institute for Health and Clinical Excellence (NICE) published a clinical guideline on the diagnosis and management of CFS/M.E. for NHS healthcare professionals in England and Wales ([www.nice.org.uk/CG053](http://www.nice.org.uk/CG053))

In 2010, NHS Scotland produced a Good Practice Statement for healthcare professionals, facilitated by Action for M.E. ([www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx](http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx))

## CIPD guidance

The Chartered Institute of Personnel and Development (CIPD) joined forces with the British Occupational Health Research Foundation, Health and Safety Executive and Healthy Working Lives in 2010 to produce guidance on *Manager support for return to work following long term sickness absence*.

It says the necessary skills and behaviours include: staying in touch regularly with the individual while they are off sick; reassuring them that their job is safe; preventing them from rushing back to work before they are ready; providing a phased return to work; helping them adjust to the workplace at a gradual pace; asking the individual's permission to keep the team informed on their condition; encouraging colleagues to support the individual's rehabilitation; holding regular meetings to discuss the individual's condition and the possible impact on their work.

## Reasonable adjustments

Under the Equality Act, as under the Disability Discrimination Act, employers should make 'reasonable adjustments' to the workplace and to working practices or arrangements, so that a disabled employee or job applicant is not at a disadvantage.

NHS Plus' evidence-based guidance for employers, *Occupational aspects of chronic fatigue syndrome/myalgic encephalomyelitis*, says reasonable adjustments may include measures such as: changing locations of work, working from home, modifying work hours, reducing workloads, reducing physical tasks, making provision for a wheelchair, flexibility in working patterns.

For people with mild or moderate M.E., the earlier such adjustments are made, the easier it will be for them to remain productive.

For more on reasonable adjustments see p 12.

## Assistance via Access to Work

Potential changes to physical features, eg. making premises wheelchair accessible or providing practical aids and equipment to help the disabled person do their job, may be funded through the Access to Work Programme.

Access to Work provides practical advice and financial support to help overcome the barriers to work experienced by people who have long term health problems.

The programme is flexible to try and meet the needs of the disabled person and their job.

Contact the Disability Employment Adviser at your local Jobcentre Plus office or go to [www.direct.gov.uk](http://www.direct.gov.uk) for advice in England, Scotland or Wales or go to NI Direct ([www.delni.gov.uk](http://www.delni.gov.uk)) for Northern Ireland.

## What should you do?

**1. Discuss** the following with the person with M.E.

- flexible hours and time keeping (p 12)
- workload (p 12)
- changing the working environment (p 13)
- further support eg. regular review meetings and documentation (p 14)
- confidentiality – does anyone else need to know? (p 14)
- possibilities of support from an occupational health professional (p 15)
- sickness absence arrangements (p 16)
- M.E.-appropriate phased return to work after absence (p 16)
- sick pay and if applicable welfare benefits (pp 16-17)

**2. Liaise** with your occupational health department or contractor.

**3. Contact** your local Access to Work centre or the Disability Adviser at your local Jobcentre Plus office for advice.

## Important

If you discuss changes that may affect your employee's income, they must be explained clearly from the outset.



# Reasonable adjustments

This section discusses some adjustments which may help your employee, depending on their individual symptoms and the severity of their illness.

## Flexible hours and time keeping

To optimise their available energy, consider allowing a person with M.E. to:

- change their working hours to avoid rush-hour travel
- work flexi or reduced hours
- work from home if possible
- have a fixed shift, where shift-work is involved
- take longer or more frequent breaks away from the desk/computer/workstation
- attend medical appointments during working hours if required.

Make sure changes do not cause resentment amongst other staff by including reasonable adjustments for disability and long-term conditions in your sickness policy and by fostering good communications amongst colleagues.

## Workload

NHS Plus' occupational guidance on CFS/M.E. for employers lists "modifying work hours, reducing workloads, reducing physical tasks" among the reasonable adjustments an employer might be expected to make for a person with M.E., as well as changing the location of work, working from home and offering flexibility in working patterns.

Discuss workload and how it fits into your employee's pacing programme (see p 6). Re-assigning tasks to another member of staff on a temporary or permanent basis can ease pressure and may help to reduce the need for time off. This may lead to a discussion about who else needs to know about your employee's situation.

Make it clear to your employee if there would be any adjustments to pay or benefits if their workload is reduced.

## Changing the working environment

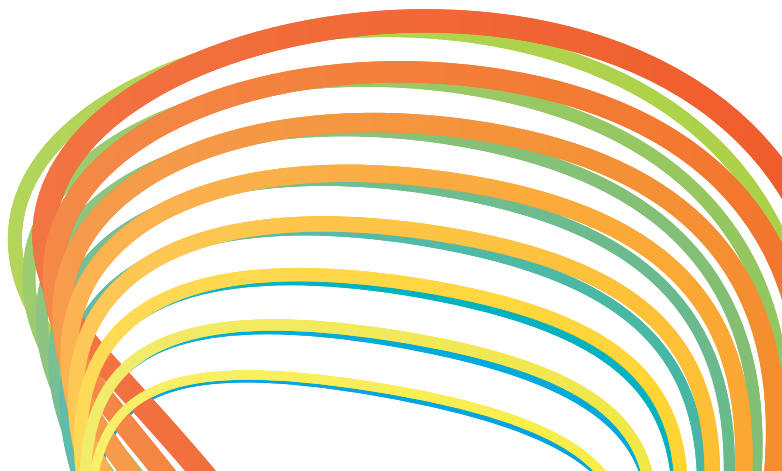
Small modifications to the working environment can make a big difference. Examples might include:

- providing a quiet area where your employee can rest without being disturbed
- permission to use an allocated parking space near to the entrance of the building
- altering the type of lighting or the location of the employee's workstation if they are light or noise sensitive
- giving as much notice as possible of any disruption to the working environment or routine.

The Access to Work programme can provide help with adapting premises to accommodate a wheelchair (if required) or provision of other practical aids and equipment (see p 10).

A responsible employer is disability-aware. If the employee who has M.E. agrees, help to raise awareness about M.E. by displaying our awareness-raising posters and leaflets, available free from our Membership Coordinator on 0845 123 2380.

**"I had to hand in my notice in my previous employment as I had no support and the post and hours caused me to suffer a relapse. I then gained employment part-time which allowed me to manage my pain and energy levels better. I am lucky that my present employer is understanding and flexible."** Caroline



# Further support

Enabling participation in staff meetings (even by phone or video conference) is a valuable way of ensuring that someone with M.E. is kept up-to-date, involved and part of the team. This is particularly important if they are working reduced hours.

Regular performance reviews provide an opportunity for both employer and employee to discuss whether the workload and hours are sustainable.

Where employees experience cognitive problems as part of their M.E. it can be helpful to:

- ensure that they receive notes or a summary of meetings wherever possible
- check that key information has been received
- provide written as well as verbal instructions.

Documenting decisions made about the role of the employee, their working environment and any reasonable adjustments, is of particular importance.

## Confidentiality

When a member of staff discloses their M.E., they may – or may not – want you to share this information with other colleagues.

Disabled people have the right to insist that their illness remains 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 a person's M.E. should not be shared with any other person, inside or outside the organisation, without the prior, expressed consent of the person with M.E.

Some colleagues may need to know about any adjustments to hours, work practices or environment that are agreed. However, they do not need to know the precise medical reason why.

Having a documented sickness policy can help to set out clearly what is to be expected in these circumstances.

Any information you intend to share should be agreed in advance with the employee concerned.

## Occupational therapy

Occupational therapists (OTs) advise employers (managers and human resources), work with occupational health and assist employees who have an illness or disability.

The Health and Safety Executive website (see p 26) has a useful page which explains the role of OTs in:

- risk assessment and risk monitoring
- retention programmes and absence management
- return to work programmes
- workplace modifications.

They also explain how to contact an OT through Jobcentre Plus, your local authority social services department and other means.

The College of Occupational Therapists has an online directory of independent practitioners at [www.cotss-ip.org.uk](http://www.cotss-ip.org.uk).

**“When I was diagnosed I was already working a phased return to work over an eight week period. However once I had got back to full time it wasn’t long before I relapsed again. My GP said that I could only go back to work for 2 hours a day, 3 days a week. I was horrified by this and my thought was once again to get back up to full time hours, not fully appreciating the fluctuating nature and unpredictability of the illness.**

**“I was fully supported by my employer and had regular meetings with the HR department, sometimes daily meetings. It wasn’t fully understood what was really happening to me and my employer voiced great concerns as to my wellbeing.” Tracey**



# Sickness absence

When an employee is genuinely experiencing difficulties in carrying out their job because of their symptoms or frequent bouts of sick leave, this is a capability issue – not a disciplinary matter or poor conduct.

An employer who fails to follow fair and proper procedures, and subsequently dismisses an employee, may be liable to legal action.

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 this illness can be counter-productive and damaging, potentially causing longer absences and slowing recovery.

If you take a flexible supportive approach, make reasonable adjustments and support an M.E.-appropriate phased return to work, it is far more likely that your employee will be able to continue working.

ACAS produce a wealth of information about managing sickness and Employment Tribunals will expect their guidelines on dealing with absence from work to have been followed. Their helpline number is 08457 47 47 47.

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

Returning to work after a period of illness with M.E. requires a much more gradual approach than most other phased returns. It is important that work and travel to/from work is incorporated in the employee's pacing programme (see p 6). A return to previous hours within eight weeks is unlikely – even eight months may be ambitious for some people. A gradual but sustainable return is recommended.

- agree a flexible, structured plan
- be clear on pay.

It is a good idea to have a structured plan so that both you and your employee understand and agree the process. However, it is also important to expect some flexibility in these plans, making allowances for setbacks or relapses – and bearing in mind that your employee may overdo it in an effort to prove all is normal again!

Short but manageable regular periods of work are most productive eg. 2 x 1 or 2 hours of flexible work a week, some from home, for several weeks, until the employee can increase their activity level by 10% and sustain it over time.



NHS Plus occupational health guidelines say that in developing a return to work plan, the following should be considered:

- building up work, or work related skills, at home at first
- starting with shortened hours and gradually building them up
- starting with a reduced workload and gradually increasing it
- ensuring that regular breaks are taken
- ensuring that the individual has a regular review with an occupational health professional.

Helpful adjustments or periods of flexible working (possibly from home) can also help to ensure a smooth transition.

Whatever the terms of your employee's return to work, make it clear what payment arrangements will apply and for how long.

If repeated attempts at a phased return to work fail, consider whether your expectations or those of the worker or other colleagues are too high.

## Sick pay

It is vital that your employee is made fully aware of what payments they will receive whilst they are sick and when all entitlement ends.

They may return on reduced hours with a reduced income. If so, it is important to discuss this with them and make it clear to them what they will be paid.

## Statutory Sick Pay (SSP)

Your employee may be entitled to Statutory Sick Pay (SSP), as long as they have been earning at least the lower earnings limit. You have a duty to keep sickness records for this purpose.

SSP is paid by the 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 & Customs (HMRC). Detailed information can be found in the E14 Employer Handbook for statutory sick pay which is available from HMRC and via their website ([www.hmrc.gov.uk](http://www.hmrc.gov.uk)).

Your employee could also be entitled to certain welfare benefits whilst on SSP.

If your employee is still sick at the start of the 23rd week of entitlement to SSP you will need to complete and send form SSP1 to your employee.

If you stop paying SSP for any other reason you will also need to complete and send this form. This will allow your employee to claim state benefits eg. Employment and Support Allowance (ESA).

## Contractual sick pay

Depending on the terms of the employment contract you operate, your employee may be entitled to Contractual Sick Pay in addition to SSP, or when SSP is not payable, eg. after 28 weeks of sickness.

They may be entitled to make an application for welfare benefits or benefits under any permanent health insurance scheme you operate.

## Welfare benefits

Employees may be entitled to benefits whilst on Statutory Sick Pay.

The Permitted Work rules allow people on some sickness benefits to earn a certain amount before their benefit is affected.

The welfare system is undergoing extensive reform but current (May 2011) means tested benefits include Income Support, Housing Benefit and Council Tax Benefit.

Your employee may also be eligible for Disability Living Allowance (DLA), which the Government plans to replace with a Personal Independence Payment by 2013.

DLA is not means tested and could be payable to your employee whilst they are in or out of work. It is designed to help with the extra costs that arise from being disabled.

Your employee may also continue to qualify for Working Tax Credit whilst they are off work sick for up to a period of 28 weeks.

Working-age benefits will be replaced by Universal Credit from 2013.

If your employee is absent from work through sickness for a long period of time they may apply for Employment and Support Allowance (ESA).

As they recover, a return to work may affect their benefits. It is important that they know and understand changes to their income, both from you as their employer and from the state.

Further information about state benefits is available on our website, [www.actionforme.org.uk](http://www.actionforme.org.uk) and at [www.direct.gov.uk](http://www.direct.gov.uk)

People with M.E. can also call our Welfare Rights helpline. Go to [www.actionforme.org.uk](http://www.actionforme.org.uk) or tel 0845 123 2380 for opening times.

# Recruiting someone who has M.E.

If you are considering offering employment to someone with M.E., you may have practical questions. Many JobcentrePlus offices have a Disability Adviser who can help.

The provision of the Equality Act relating to disability may apply when someone has a diagnosis of M.E., which means some reasonable adjustments to normal working conditions may be required (see p 10, 12). Help with costs may be available through the Access to Work programme (see p 10).

Businesslink.gov.uk has a useful section on recruiting and employing people with disabilities, while ACAS offers advice on preventing disability discrimination.

## Health-related questions

Once you have offered a person a job you are allowed to ask appropriate health-related questions.

You may not ask health-related questions before you have made an offer, except to: decide whether an applicant can carry out an essential function of the post, or you need to make reasonable adjustments to the selection process, or to monitor diversity or to take positive action to assist disabled people.

A person can complain to the Equality and Human Rights Commission (EHRC) if they think you are asking questions unlawfully. The EHRC may in turn take enforcement action against an employer, in appropriate cases, to stop such questions being asked.

If you ask health-related questions during the recruitment process and do not then offer a disabled person the job, they may bring a claim of discrimination against you. The burden of proof, to show that the reason for the rejection of the disabled person was not discriminatory, will fall on you.

## Offers of employment

Any offer of employment can be conditional as long as the conditions are stated in the letter. If you specify a probationary period or insist on a medical examination, this must apply to all prospective employees not only those who have an existing medical condition.

# Rights of carers

If your employee is a primary carer for someone with M.E., they will be shouldering extra responsibilities as well as coping with the practical and emotional implications of illness in the family.

Carers have a legal right to take (unpaid) time off for dependants (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
- time off in emergencies
- parental leave.

A request for flexible work may involve a change in hours, time or place of work, including working from home.

Staff have a right to take "a reasonable amount of time off work to deal with certain unexpected or sudden emergencies and make any necessary longer term arrangements." In the case of a dependant with M.E. this could apply if the person with M.E. has a relapse, needs to be accompanied to a medical appointment, or if usual care arrangements break down eg. someone who looks after the sick person fails to turn up as arranged.

Parents of young or disabled children are entitled by law to a period of unpaid parental leave. Parents with long-term sick or disabled children are entitled by law to request flexible working arrangements in some circumstances. Although there is no automatic right to flexible working, an employer has a duty to give serious consideration to such a request.

Businesslink.gov.uk has a useful guide to the law and best practice on flexible working, as does ACAS and direct.gov.uk

Sources of help for carers may be found in the family and friends section of our website, [www.actionforme.org.uk](http://www.actionforme.org.uk) and in our booklet for carers, which is free to download or available for a small charge from 0845 123 2380.

# How other employers help their staff

This chapter includes some accounts by a variety of employees with M.E. followed on pp 23-25 by a more detailed case study featuring an employee and manager at Deloitte.

If you are an employer who has supported someone with M.E., or an employee who has benefitted from such support, please tell us so that we can highlight this good practice in our communications.

Either send your account via our website [www.actionforme.org.uk](http://www.actionforme.org.uk) or call our Communications Officer on 0117 930 1322.

## 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."

## Sally

"I am one of the lucky ones. 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 last 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."

## Suzanne

"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 worse, 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 as 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

"When I got ill I was lucky enough to be working for a multi-national 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."

## A receptionist's story

"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 a 'come in when you are able and stay for as long as you can manage' basis. This usually worked out at 1-2 hours in the beginning, with relapses, then building over the next six months to 4-5 hours daily.

"I soon realised that I would have to cut back permanently. I now work 20 hours over four days." (This employee asked to remain anonymous)

### Case study: Joanna and Deloitte

Joanna writes: "I joined Deloitte in April 2007 and worked in their Banking & Securities Audit department until the onset of my illness in June 2008. I had six months off work and began my return to the same role on a phased basis in January 2009.

"I built up my hours slowly and was almost back up to five-day weeks when I succumbed to a nasty case of shingles in March 2009, the result being another two months off work.

"I have since returned to full time hours and have, with the full support and encouragement of the firm, moved to a different role which is office-based with more predictable hours.

"The key for me has been gradual increase and tailoring as opposed to rigid schedules.

"I remember being slightly affronted by the occupational health consultant's suggestion that I begin with 2 hours per day, 2 days per week when I had been fully expecting and planning my triumphant return. However by the end of my first week I was utterly wiped out and extremely grateful that the consultant had had the foresight to squash my rather over-ambitious plan of action.

"Deloitte has been fantastic – I don't really know where to begin.

"Initially, they arranged for me to visit an external occupational health consultant who wrote a series of reports detailing my illness, recovery/prognosis and adjustments that would need to be made once I returned to work. These were taken very seriously by the HR team who kept in regular contact with me during my absence and ensured all recommendations were implemented upon my return.

"I still see consultants from the practice on a regular basis and Deloitte now have an occupational health nurse on site at their London campus.

"When I began my return to work, I was placed under the wing of Louise Clark, a Senior Manager within my department, who has consistently tried to understand and support me in any way she can, both professionally and personally. She has been my champion and the driving force which has kept me on track.

"Louise is also my workability mentor – a scheme set up by the Workability Network, one of Deloitte's diversity initiatives aiming to support employees with disability issues and their managers.

"The network has also run an Understanding M.E. evening workshop (led by Action for M.E. trustee, Tony Golding) and established a rest room facility for employees who need brief periods of rest.

“The effect of having a supportive employer should never be underestimated – it is simply vital.

“During recovery, the pressure people with M.E. place on themselves is bad enough without added pressures of a ‘must get back to work at any cost’ mentality from their boss.

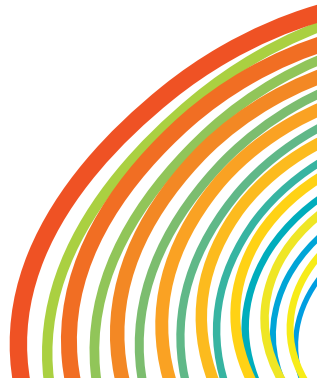
“Being allowed the time and space to recover has been a gift. In my darkest days, I felt that my future had been taken from me and that planning would only lead to disappointment. However, now I’m back on my road to recovery, I am able to think at least in the medium term.

“I have been working full time for the last eight months with minimal disruption, and have found that the same level of support and understanding has been extended to me in my new department as I was lucky enough to have been given in my previous role.

“More and more I get the feeling that not only do Deloitte have enlightened policies and procedures in place, but that a supportive and understanding culture permeates throughout.

“I would like to say thank you to Deloitte. The help and support I have been given have enabled me to retain my self-worth and dignity which would have been crushing to lose at such a difficult juncture.

“I wish that we lived in a world where all people with M.E. could be offered similar opportunities, but I believe with enlightened employers such as Deloitte leading the way we have a hope of setting an example for other firms to follow.”





## Deloitte's perspective

Val Stevenson, Human Resources Director, says: "Deloitte has a commitment to our diversity, respect and inclusion agenda – we support our employees who have long-term health conditions and help them achieve their work related goals. We pride ourselves on being an open and flexible employer and we are keen to provide an inclusive workplace where our employees feel comfortable discussing any issues they may have.

"We have a dedicated occupational health advisor who assists in rehabilitating individuals who have been on long-term sick leave back to work. In the London office, we have an onsite health suite that provides a private medical practice and other health related services. Within the health suite we have a rest room for employees who have medical conditions or disabilities that require them to take periods of rest during their working day.

"We have flexible working policies and the technology in place for our employees to work from home. As part of the rehabilitation process we encourage our people to use this to enable them to have a gradual return to work.

"Jo is an active member of our Workability network, a network for people with disabilities and medical conditions. She is a great role model to all our employees."

(Reproduced from an article in our membership magazine, *InterAction*, updated April 2010).



# Useful contacts

## **Action for M.E.**

General enquiries: 0845 123 2380 or 0117 927 9551 (Mon to Fri 9am to 5pm)

Email: [admin@actionforme.org.uk](mailto:admin@actionforme.org.uk)

Welfare Rights Line: 0845 122 8648 (call for opening times)

Online M.E. Centre: [www.actionforme.org.uk](http://www.actionforme.org.uk)

## **NHS Plus**

T: 0800 077 88 44

[www.nhsplus.nhs.uk](http://www.nhsplus.nhs.uk)

## **ACAS**

T: 08457 47 47 47

[www.acas.org.uk](http://www.acas.org.uk)

## **Business Link**

T: 0845 600 9 006

[www.businesslink.gov.uk](http://www.businesslink.gov.uk)

## **HM Revenue & Customs**

T: 08457 143 143

[www.hmrc.gov.uk](http://www.hmrc.gov.uk)

## **Equalities and Human Rights Commission**

T: 0845 604 6610 (England)

T: 0845 604 5510 (Scotland)

T: 0845 604 8810 (Wales)

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

## **Directgov**

[www.direct.gov.uk](http://www.direct.gov.uk)

## **Health and Safety Executive (HSE)**

T: 0845 345 0055

[www.hse.gov.uk](http://www.hse.gov.uk)

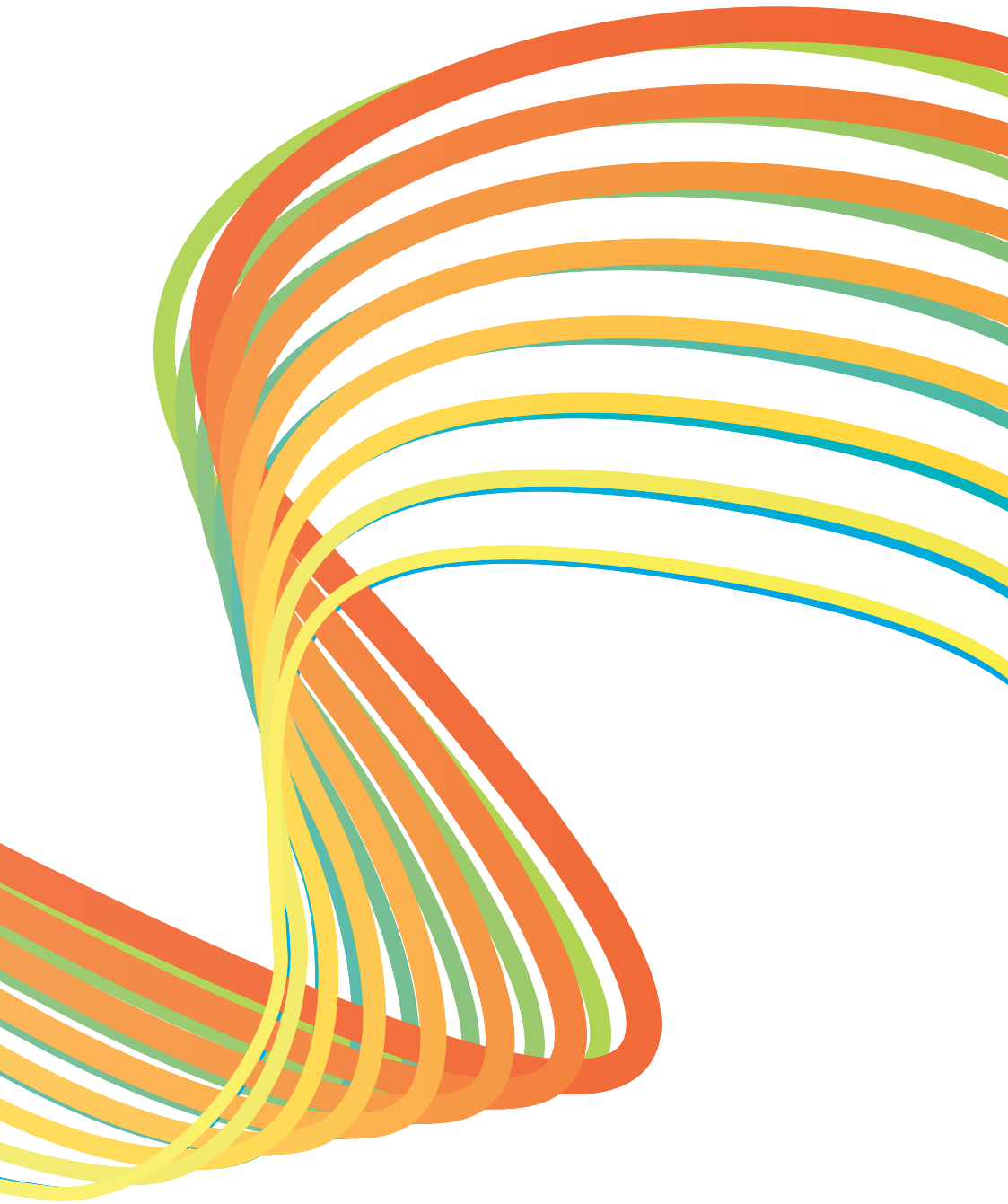
## **Information Commissioner's Office**

T: 0303 123 1113

[www.ico.gov.uk](http://www.ico.gov.uk)

## **College of Occupational Therapists**

[www.cotss-ip.org.uk](http://www.cotss-ip.org.uk)



[www.actionforme.org.uk](http://www.actionforme.org.uk)

“We have flexible working policies and the technology in place for our employees to work from home. As part of the rehabilitation process we encourage our people to use this to enable them to have a gradual return to work.” Val Stevenson, Deloitte



PO Box 2778  
Bristol  
BS1 9DJ

T 0845 123 2380  
E [admin@actionforme.org.uk](mailto:admin@actionforme.org.uk)  
[www.actionforme.org.uk](http://www.actionforme.org.uk)

**Registered address**

Third Floor Canningford House  
38 Victoria Street Bristol BS1 6BY  
Registered charity in England and Wales no. 1036419  
Registered in Scotland no. SC040452  
Company limited by guarantee, registered in England  
no. 2906840  
©Action for M.E. 2013

