



M.E. and work

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

Having a long term illness, or caring for someone with M.E., often affects your work – and, potentially, your income.

It can be tough. You will need to make compromises and your priorities are likely to change. It is important to consider your limits and be realistic about your health and/or abilities.

Some people with M.E. will not be able to work at all and will have to rely on savings, welfare benefits, insurance or private income.

Some will be well enough to do an hour or two of voluntary work, at home or in the community, at times which accommodate the fluctuations of their illness.

Some people with mild to moderate M.E. are able to work part-time or even full time as they move into recovery.

This booklet is for people with M.E. who are in work or considering employment. It has been produced with help from people with M.E., Nikie Catchpool, Joint Speciality Lead and Occupational Therapist, Bath and Wiltshire CFS/M.E. Service and Emma Ife and Isabel Regan, employment specialists at Allen & Overy LLP.



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Who are we?

Action for M.E. is the UK's leading charity for people with M.E. and their carers.

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 on 0845 123 2380 or 0117 927 9551 (Mon to Fri 9am to 5pm). Or download them from our Online M.E. Centre at www.actionforme.org.uk

We also have a Welfare Rights Line on 0845 122 8648 (call for opening times) for information and advice on welfare benefits, disability discrimination, employment and insurance issues.

You, M.E. and work

M.E. is defined as a neurological illness by the World Health Organisation. 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. In the working population, as many as 1 in 250 may have M.E.

Symptoms can 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. Levels of severity range from mild and functioning to housebound or bedbound.

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



This booklet outlines the legal rights of people who may qualify as disabled under the Equality Act 2010 and the support which may be available to help you stay in work, if you lose your job and when you are well enough to return to work.

Understanding M.E. and the treatments available to help you manage your symptoms is important. More information is available in our booklets, *All about M.E.* and *Pacing for people with M.E.* Another of our booklets, *An employer's guide to M.E.*, may also help your manager. To order your copies, call 0845 123 2380 or download them free from our website www.actionforme.org.uk

Managing your symptoms

There are no wonder drugs or treatments that can cure M.E. but there are many approaches open to you and your doctor that can make a difference to how you feel and give you back control over your situation.

It is important to establish a relationship with your doctor so that you can discuss all the management approaches available and 'problem solve' any issues together.

If left untreated, symptoms such as pain, sleep difficulties and mood problems can take over your life and get in the way of recovery. Your doctor and other healthcare professionals can help to treat these symptoms by prescribing medication and suggesting changes in your lifestyle.

Some areas have specialist NHS clinics which offer fatigue management. Strategies that may be used include activity/energy management (pacing), graded activity/exercise therapy (GAT/GET) and cognitive behaviour therapy (CBT). These therapies should be supervised by practitioners trained in CFS/M.E.

Pacing

Learning to successfully manage activity and rest is often referred to as pacing. Pacing is an energy management technique which 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.

A short introduction to pacing is given in Appendix 2 on p 35.

Legal context

Your employer's legal responsibilities to you as an employee with M.E. include the standard obligations under your contract of employment – plus the additional responsibilities they may have towards you as a person with a long-term fluctuating condition if you 'qualify' as disabled under the Equality Act 2010.

Please note: 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 professional legal advice.

Equality Act 2010

The Equality Act 2010 has incorporated and built upon the Disability Discrimination Act 1995 and nine other pieces of 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 2010 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. '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.

What does this mean for you?

The Advisory, Conciliation and Arbitration Service (ACAS) says the Act:

- puts a duty on employers to make reasonable adjustments* to help staff overcome disadvantage resulting from an impairment. (*Find out more about reasonable adjustments on p 9).
- 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.

The Act brings in new protection for disabled employees, 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 Plus guidelines

In addition to guidelines for GPs and other healthcare professionals involved in diagnosis and symptom management (see below) the NHS has produced guidelines for employers and employees.

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."

NB. Links to NHS Plus guidelines, the National Institute for Health and Clinical Excellence (NICE) clinical guideline and NHS Scotland's Good Practice Statement for healthcare professionals may be found on our website, www.actionforme.org.uk

CIPD guidance

In 2010 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 to produce guidance on *Manager support for return to work following long term sickness absence*.

It tells managers that 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.

Rights of carers

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.

Sources of help for carers may be found in the family and friends section of our website, 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.

Reasonable adjustments

Under the Equality Act 2010 (see p 6), if you have “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” – including a long-term fluctuating condition – you may be regarded as disabled under the Act.

If this applies to you then, as under the Disability Discrimination Act, your employer should make ‘reasonable adjustments’ to the workplace and to working practices, so that you (as a disabled employee or job applicant) are not at a disadvantage.

Adjustments might include:

- flexible hours and time keeping
- changes to your workload
- changes to your working environment
- regular review meetings
- support from an occupational health professional.

These are described in more detail on pp 10-12. Talk to your employer sooner rather than later. The earlier such adjustments are made, the easier it could be for you to manage work alongside your symptoms and the better your chances of staying in work.

Access to Work Programme

Advice and financial help may be available 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.

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

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



Flexible hours and time keeping

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

- change your working hours to avoid rush-hour travel
- work flexi or reduced hours
- 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/workstation
- attend medical appointments during working hours if required.

Speak to your boss to see what can be arranged.

Please note: it is very important to find out from the start if there would be any changes to your pay or benefits if your role changes or your workload is reduced.

Changes to your contract or the way you work may cause resentment amongst other staff unless they understand why it is happening. How much you tell them is down to you (see p 14). Your employer could help by including reasonable adjustments for long-term health conditions and disability in the organisation's sickness policy.

Workload

You need to incorporate work into your pacing programme (see p 35).

NHS Plus' occupational guidance on CFS/M.E. 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 your workload with your manager. Re-assigning tasks to another member of staff on a temporary or permanent basis can ease the pressure on you and may help to reduce your need for time off. This may lead to a discussion about who else needs to know about your situation.

Again, make sure you know if there will be any adjustments to your pay or benefits if your workload is reduced.

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 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 your workstation if you are light or noise sensitive
- giving as much notice as possible of any disruption to your 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 9).

If you would like to raise awareness about M.E. in your workplace, display our awareness-raising posters and leaflets. They are available free from our Membership Coordinator on 0845 123 2380.

Review meetings

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

If you can manage it, participation in staff meetings – in person or by phone – is a valuable way of keeping up-to-date, involved and part of the team.

This is particularly important if you are working reduced hours.

If you have cognitive problems, find out if it is possible for you to get a summary of meetings. Receiving written as well as verbal instructions may also be helpful.

Is there any information you must have, that you may miss if your hours are reduced or you are off sick? Can someone ensure that you get it?

It is important to get decisions made about your role and income in writing.

Keep a brief, dated record of any discussions about changes to your job, support offered, review meetings and return to work.

Occupational therapy and work advice

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

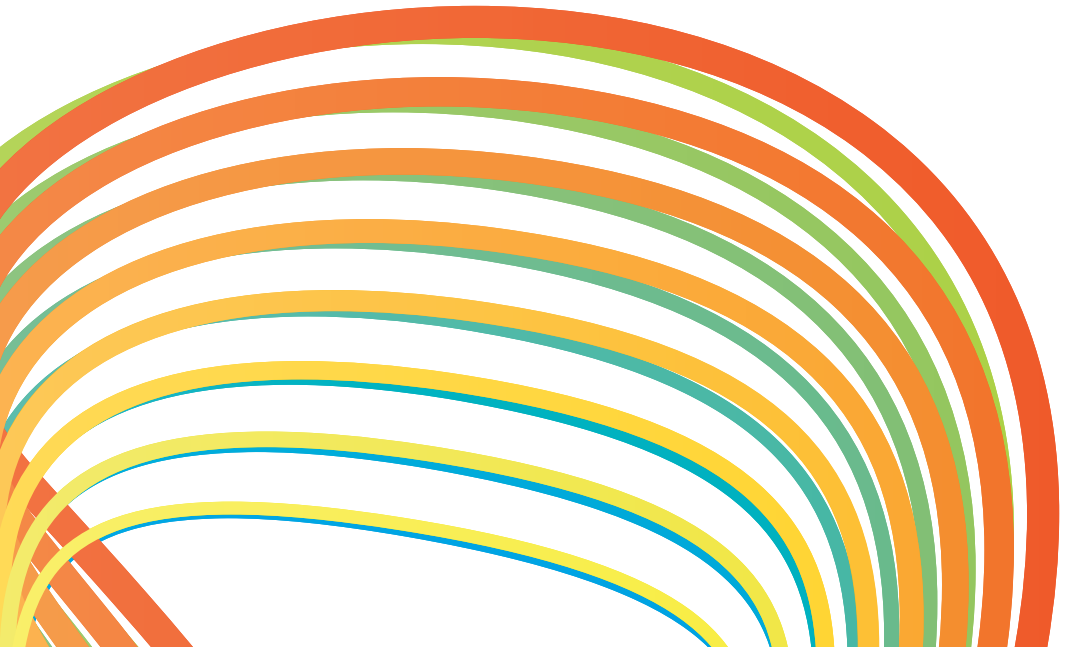
The Health and Safety Executive website (see p 37) has a useful page which explains the role of OTs in:

- 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. Another source for occupational therapy is via a specialist NHS CFS/M.E. clinic.

The College of Occupational Therapists has an online directory of independent practitioners at www.cotss-ip.org.uk

For general advice from an OT, see opposite.



If you have a job

When you have been diagnosed with a chronic illness, you may feel worried or unsure about telling people at work (see p 14).

It is important to know where you stand legally (p 6) and whether your employer is willing to make reasonable adjustments (p 9).

Incorporating work into your pacing programme (see p 35) can be a challenge. If you can, get the help of an Occupational Therapist (OT) who understands M.E.

Other factors to consider include:

- maintaining good communications with colleagues (see p 15)
- what happens if you have to take time off sick (p 16)
- what to do if you're bullied (see p 19).

This section looks at some of these issues.

In work? An OT's advice

The following text from Specialist Occupational Therapist Bev Knops, has been extracted from *Pacing v work: the impossible dilemma?*, published in Action for M.E.'s membership magazine *InterAction*, Summer 2010:

"Many of our clients consider either a temporary or permanent reduction in working hours which will minimise the risk of overexertion. This may leave enough energy to participate in other activities or at least avoid collapse on returning home after work.

"Obviously employees are concerned about a reduction in pay; however, it is possible to negotiate part-time hours with full pay – temporarily, anyway. Regular rest breaks are so useful. Negotiation with employers for more frequent rest breaks, and timing these according to their own needs rather than a pre-determined schedule, may be possible.

"Where to take good quality rest breaks in a busy, noisy work environment? I have worked with people who successfully rest in toilets and stairwells. Personally I would prefer to retreat to my car. Use of an iPod or similar can block out background noise, and can also be used to listen to relaxation recordings during a break.

“Being able to say no to additional work tasks, particularly when you feel pressurised to prove you can continue to work effectively, is difficult. However, we have found that this ability, plus other communication skills are particularly beneficial in sustaining work and working relationships.

“Good communication with employers, and in particular line managers, is essential. It may be helpful to organise a meeting with your employer to discuss how you are currently coping and what changes may enable you to sustain work. This seems to bring greater understanding than focusing on barriers, or assuming that employers should know how to help. Remember you still have valuable work skills – don’t be afraid to discuss those, too.

“Pacing in the work place can be a huge challenge but the structure and routine of work can also support pacing. I have several clients who can pace beautifully at work during the week but it all goes to pot at the weekends.”

Disclosing your illness

You may think of yourself as ill rather than disabled but having a long-term fluctuating illness which adversely affects daily life may be regarded as a disability under the Equality Act 2010 (p 6).

The Equality Act 2010 aims to protect people who have a disability from discrimination (both direct and indirect) in the workplace. Potential employers are not allowed to ask health-related questions, except in specific circumstances.

Disclosing a disability lets employers know they need to make reasonable adjustments to the recruitment process or to support a disabled person in work. Disabled people and their employers are entitled to apply for help from the government through Access to Work. They are also entitled to apply for disability benefits.

You don’t have to disclose a health problem or disability to an employer, unless it could cause health and safety problems eg. if your M.E. causes cognitive problems, there would be an issue if you couldn’t concentrate and your safety or someone else’s might be at risk as a result.

You may be worried in case disclosing your M.E. will put you at a disadvantage, label or stigmatise you, especially if bullying is a problem at work. Or you may be concerned about what will happen to the information you will provide.

If you tell your boss or employer about your illness, you can ask them to treat the information as confidential.

Confidentiality

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.

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, unless you want them to.

Maintaining good communications

Whether or not you disclose your M.E. at work, maintaining communications with your employer and workmates is important in terms of professionalism and good will.

People are not interested in the daily ups and downs of someone else's illness but your line manager does need to understand the fluctuating nature and impact of your symptoms. Giving them a link to the employers' section of our website, www.actionforme.org.uk, or a copy of our leaflet on *M.E. and work* or our *Guide for employers* may help.

Some people will need to know if there are going to be changes to your hours, duties or place of work and if there will be a practical implication for them.

It may be unnecessary, or it may be diplomatic, to inform others.

You may need help to do your job or to make sure you don't miss out on key meetings and documentation.



If you are off sick

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, potentially causing longer sickness absences and slowing 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.

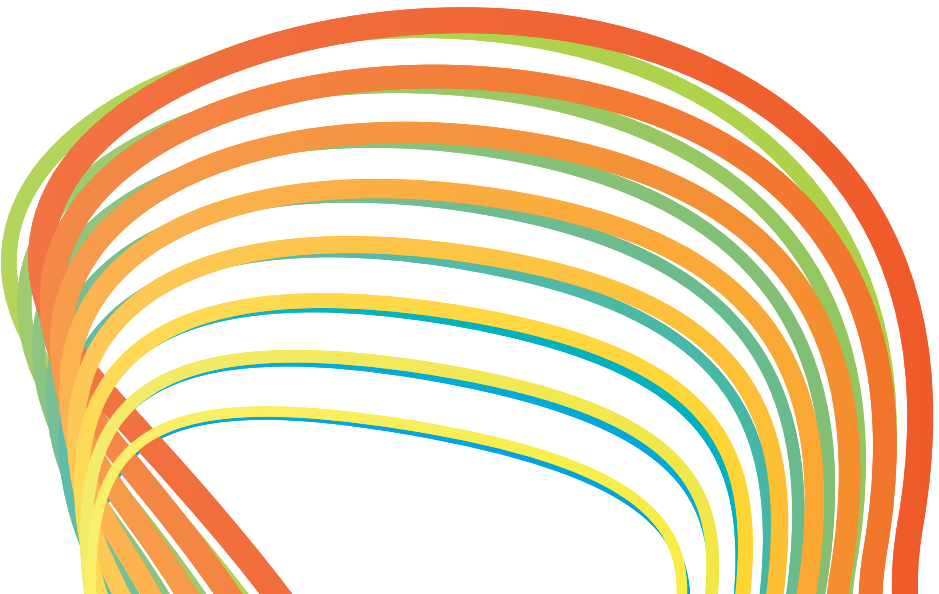
You must tell your employer straight away if you are too ill to go to work.

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 ill for up to 5-7 days, you can usually complete a form on your return (self-certification), so you can get sick pay. After this time, you will usually have to get a fit note from your GP.

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



Fit note

The fit note (or 'Statement of Fitness for Work') was introduced in place of the doctor's sick note on 6 April 2010.

The main changes mean your GP will be able to say if they think you are 'not fit for work' or 'may be fit for work taking account of the following advice' – with tick boxes for:

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

Your doctor may make suggestions about the types of support your employer could provide to help you back to work.

Your employer isn't obliged to do what the doctor suggests but if they don't, they should act as if you are not fit for work.

The fit note allows your GP to comment on the functional effects of your illness.

Long-term sickness

When an employee is genuinely experiencing difficulties in carrying out their job because of a long-term fluctuating health problem, this as a capability and a disability issue – not a disciplinary matter or poor conduct.

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 'getting back to work' programme with you.

Your employer should make reasonable adjustments (p 9) 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 what if any impact this will have on your income.

Action for M.E.'s Welfare Rights Line on 0845 122 8648 (call for opening times) offers information and advice on welfare benefits, disability discrimination, employment and insurance issues.

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 into your pacing programme.

A return to previous hours within eight weeks, as happens with some other illnesses, is unlikely – even eight months may be ambitious!

A gradual but sustainable return is recommended.

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 you can increase your activity level by 10% and sustain it over time.

It is a good idea to discuss a structured but flexible plan with your employer, so that both of you understand and agree the process.

It is important to expect some flexibility in these plans, making allowances for setbacks or relapses – and bearing in mind that you may feel obliged to overdo it in an effort to prove all is normal again!

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.

Reasonable adjustments (see p 9) or periods of flexible working (possibly from home) can also help to ensure a smooth transition.

Whatever the terms of your return to work, make sure you know what payment arrangements will apply and for how long.

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 over twice as likely to report bullying or harassment in the workplace.

ACAS says: "Bullying and harassment means any unwanted behaviour that makes someone feel intimidated or degraded or humiliated or offended. It is not necessarily always obvious or apparent to others, so it can happen in the workplace without an employer's awareness.

"Bullying or harassment can be between two individuals or it may involve groups of people. It might be obvious or it might be insidious. It may be persistent or an isolated incident. It can also occur in written communications, by phone, email not just face-to-face actions."

The Equality Act 2010 defines harassment as "unwanted conduct related to a relevant protected characteristic [ie. age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation] which has the purpose or effect of violating an individual's dignity or creating an intimidating, hostile, degrading, humiliating or offensive environment for that individual."

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.

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.

ACAS operates a free helpline on employment-related issues, 8am-8pm, Monday-Friday and 9am-1pm Saturday. Tel 08457 47 47 47. Their leaflet on bullying can be downloaded from their website, www.acas.org.uk. It offers advice on what to do if you are thinking about confronting the bully, making a formal complaint and if necessary, taking legal action.

For a listening ear out-of-hours, contact the Samaritans (www.samaritans.org) on 08457 90 90 90.

If working isn't working

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 how far communications have broken down:

- keep a record of any discussions, meetings, emails, letters or other communications and actions you take to try to remedy the situation
- open other channels of communication
- seek advice
- invoke your organisation's grievance procedure
- try mediation
- take legal action.

Communication

If your manager is unsupportive, is there someone else you can talk to to try to improve matters?

Your manager's manager, Personnel/HR, an employee representative or trade union official, if you have one?

Advice

Do any of the following have any advice?

- Your union, if you have one
- The Disability Employment Adviser at your local Jobcentre Plus
- An employment adviser at your local Citizen's Advice Bureau
- ACAS, the advisory, conciliation and arbitration service's helpline on 08457 474747 or, if you are in Northern Ireland, the Labour Relations Agency (LRA) – see p 37.

Grievance procedure

If speaking to your manager and others doesn't work, you may wish to consider invoking your company's standard grievance procedure. This is usually described in the staff handbook. Keeping a record, as described opposite, may be useful here.

You may be required to have raised the issue in this way if you later take legal action against your employer.

Mediation

Will your employer agree to try mediation through ACAS or the LRA (see p 37) to try to reach an amicable solution?

These organisations have specialists who will try to help you and your employer to sort out the problem.

Legal action

If your employer has failed to meet the requirements of the Equality Act 2010 and you do not reach an agreement through ACAS or the LRA, 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) between employers and employees.

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."

However, going to an employment tribunal is not an easy option and we suggest that you first seek advice from the ACAS helpline, 08457 47 47 47, Citizens Advice and/or your union if you are a member of one.

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 discrimination complained of.

If you are looking for work

Part-time work, flexible hours, the opportunity for rest breaks and the option of working from home can all help you to manage M.E. and work within your pacing programme – but finding a job which allows you to manage your symptoms and/or finding an employer who is able and willing to support someone with a complex fluctuating condition is not always easy.

In most cases employers are not allowed to ask job applicants about their health (see pp 23-23). The Equality Act 2010 (p 6) aims to prevent employers from discriminating on the grounds of long-term ill health or disability and to make reasonable adjustments (p 9) to support people in work.

Some people refresh their skills by doing a course at their local college or try volunteering first.

Jobseekers

Your local paper, Jobcentre and online job sites including the Directgov jobseeker's database are starting points.

Directgov's Next Step site offers practical advice on building your cv, application forms, covering letters and interview techniques.

If you do decide to disclose your M.E., your local Jobcentre should be able to put you in touch with a Disability Employment Adviser (DEA).

DEAs offer help and advice to unemployed people who have a disability about the range of specialist support available, eg. training, job search and referral to a work programme.

Work programmes

The Access to Work programme (p 9) provides financial support and advice to employees and employers.

Work Choice is intended for people with complex disabilities whose needs cannot be met through other schemes. It was previously referred to as the Specialist Disability Employment Programme. Everyone who has been on Employment and Support Allowance will be guaranteed a place on Work Choice if they are still unemployed after two years.

As part of its welfare reforms, the Government is replacing various work schemes for claimants of JobSeekers Allowance and Employment and Support Allowance with a single Work Programme (WP).

Participants must undertake activities specified by their adviser. When we asked the Department for Work and Pensions for clarification about such activities (June 2011), a member of the Work Programme Communication Team told us: “We are not being prescriptive in how the WP is delivered and therefore cannot specify what the WP will look like.”

The situation may become clearer as WP becomes established. Please check our website, www.actionforme.org.uk, government website www.direct.gov.uk or ask your Jobcentre Plus for up-to-date information.

Organisations which can help

As well as JobCentre Plus, there are some charities and specialist agencies which help people with disabilities back into work.

Shaw Trust is a national charity which supports disabled and disadvantaged people to prepare for work, find jobs and live more independently.

Remploy provides employment services and employment to people experiencing complex barriers to work

Your local Disability Information and Advice Line service (DIAL) may know of other organisations which offer help in your area.

Contact details may be found on p 37.

Applying for jobs

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.

Advice is available on websites like Directgov, Jobsite and (for graduates) Prospects (see p 37).

Or ask at your local Jobcentre Plus.

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.

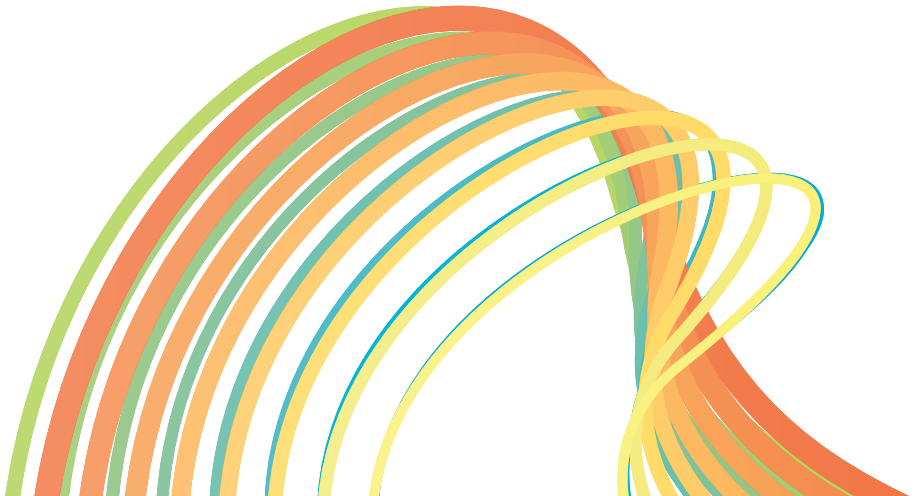
You can complain to the Equality and Human Rights Commission if you think an employer is asking questions unlawfully.

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

Any offer of employment can be conditional as long as the conditions are stated in the letter.

If there is a probationary period or a medical examination, this must apply to all prospective employees not only those who have an existing medical condition.



Volunteering

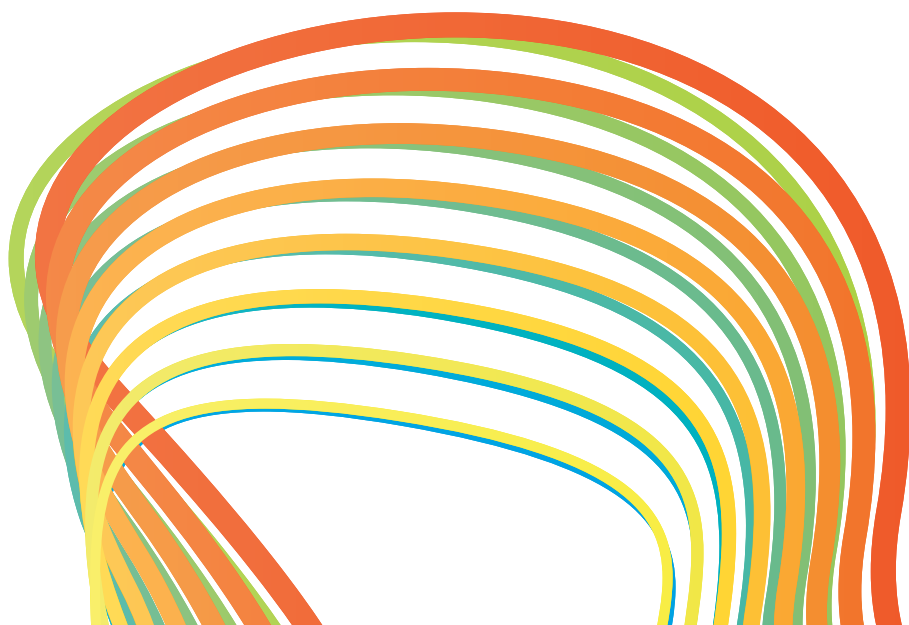
Volunteers often have more flexibility over the hours they work. If you receive certain welfare benefits, doing a certain amount of unpaid work should not affect your claim (but check with the disability adviser at your Jobcentre).

A commitment of just one or two hours a week may provide you with an opportunity to:

- do something useful, which brings a sense of achievement
- manage your energy and symptoms within your pacing programme
- build up your activity levels gradually over time
- develop or refresh your skills and experience
- build your cv
- improve your job prospects
- improve your confidence
- meet new people, in person, by phone or online.

It helps if you volunteer for something which you are interested in, which draws on your natural interests and abilities.

Further information and a searchable directory of local volunteer centres may be found online at Do-it.org.uk



If you lose your job

If your employer has acted fairly and made reasonable adjustments (see p 9) and it is just not feasible for you to continue to work for them, your employer may dismiss you on grounds of capability (ie. because you are no longer capable of doing the job you are contracted to do).

If this happens, or seems likely to happen, speak to an experienced adviser, such as ACAS, the Labour Relations Agency (N Ireland) or your local Citizens Advice Bureau, as soon as possible.

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 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.

Coping with job loss

Losing your job is often stressful. It can affect not only your income but your self-confidence, daily routine, sense of purpose, even your social life.

Feeling angry, hurt, rejected and/or anxious is entirely natural. You may even find yourself grieving for what was.

If you feel like this, don't try to bottle things up. Tell family and friends. Reach out for support.

If you are furious at your former employer, get 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 come back to haunt you).

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. Are there even some advantages to being out of the particular situation you were in?

If you are feeling low, contact the Samaritans (www.samaritans.org) anytime on 08457 90 90 90.

Money matters (in or out of work)

Having a long-term fluctuating illness can affect your income.

If you work, changes to your hours or role may affect your pay. If so, it is important to discuss this with your manager and make sure you understand exactly what you will be paid.

You should also find out about:

- statutory and/or contractual sick pay (below)
- welfare benefits (p 28)
- ill-health insurance and ill-health retirement (p 29).

Action for M.E.'s Welfare Rights Line on 0845 122 8648 (call for opening times) offers information and advice on welfare benefits, disability discrimination, employment and insurance issues.

If you are entitled to sick pay, it is vital that you are fully aware of what payments you will receive if you are off sick and when any entitlement ends.

Statutory Sick Pay (SSP)

You may be entitled to Statutory Sick Pay (SSP), as long as you have been earning at least the lower earnings limit. Your employer has 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).

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

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 this form. This will allow you to claim state benefits eg. Employment and Support Allowance (ESA).

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, eg. 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

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 (June 2011) means tested benefits include Income Support, income-related Employment and Support Allowance (ESA), Housing Benefit and Council Tax Benefit.

You 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 while you are in or out of work. It is designed to help with the extra costs that arise from being disabled.

You may also continue to qualify for Working Tax Credit whilst off work sick for up to a period of 28 weeks. Working-age benefits will be replaced by Universal Credit from 2013.

If you are absent from work through sickness you may also be eligible for ESA.

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

Further information about state benefits is available in our Online M.E. Centre at www.actionforme.org.uk and at www.gov.uk

Action for M.E.'s Welfare Rights Line on 0845 122 8648 (call for opening times) also offers information and advice on welfare benefits, disability discrimination, employment and insurance issues.

Debt problems

If you have debt problems call the National Debtline's confidential service on 0808 808 4000, 9am-9pm Monday-Friday, 9.30am-1pm Saturday.
www.nationaldebtline.co.uk

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.

Check your policies, personal and company-run, 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 remain off sick but in employment, 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 warn that you will not receive your full income from PHI, if your claim is successful, and you will have to wait some time before payments start.

Ill-health retirement

Alternatively or in addition to PHI, your employer may have a pension scheme that allows you to retire early due to ill health and claim your pension early.

If you want to retire, qualify under the criteria in your policy and your claim is successful, 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.

Potential problems

Claiming permanent health insurance or an ill-health retirement pension is not always easy, as people have told us.

Citizen's Advice has a section on how to resolve insurance problems on its website.

The Pensions Advisory Service (TPAS) provides free information, advice and guidance on pension schemes. Their helpline number is 0845 601 2923.

If you receive state benefits an occupational pension or permanent health insurance payments can affect any benefits you receive, such as contribution-based Employment and Support Allowance.

Appendix 1: How some employers help their staff

This chapter includes some accounts by a variety of employees with M.E. followed on pp 32-34 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 contact us via our website 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.

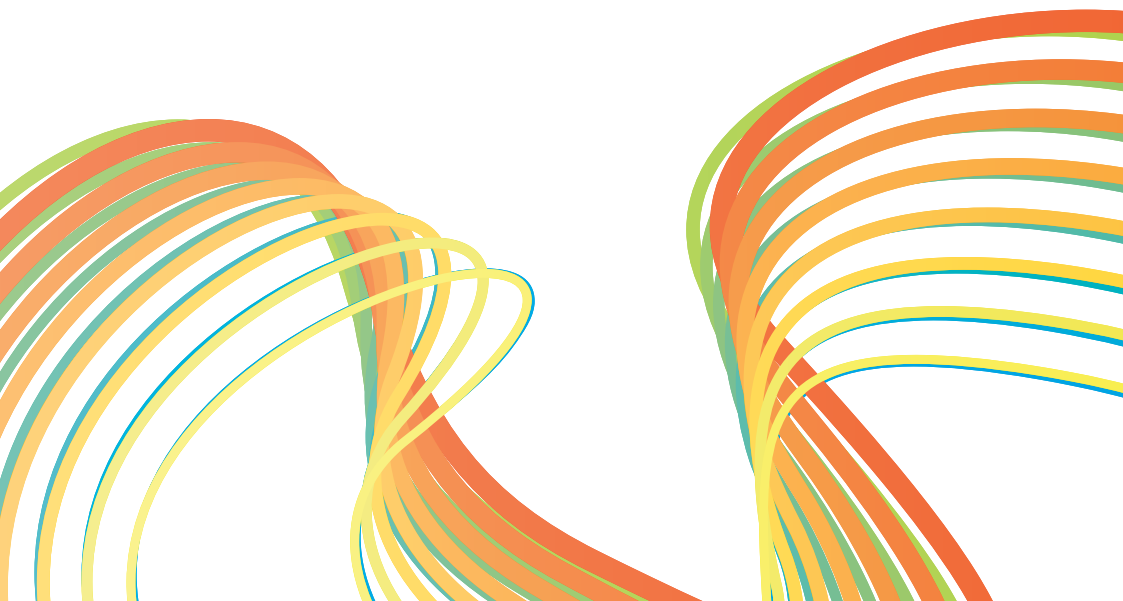
"Being allowed the time and space to recover has been a gift. In my darkest days, I felt that my future had been taken from me and that planning would only lead to disappointment. However, now I'm back on my road to recovery, I am able to think at least in the medium term.

"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).



Appendix 2:

Basic guide to pacing

People with M.E. find that their energy levels vary from day to day and it can be easy to do too much when having a better day. Unfortunately this can lead to a setback the next day or the day after, creating the vicious cycle of 'boom and bust.' Pacing organises your day into sustainable activity and regular rest to avoid this damaging pattern.

Think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait for it to recharge before you can use the phone again. If you use some of the battery and make regular top ups, then your phone will always be ready for use. Managing your energy through planned periods of activity and rest will mean you are more likely to be able to do the activities you want to do.

Pacing is highly individual and varies from person to person. However, there are key areas that form the basis of successful pacing:

Understand what 'activity' means for you

Activity doesn't just mean physical tasks; it also means tasks that involve mental exertion or social interaction. This includes not only work or domestic tasks but pastimes that you may think of as relaxing, such as talking to friends, reading, watching television or listening to music. It also includes hidden mental activity like emotion and worry. This is much harder to measure and predict, yet for many people it is the biggest drain on energy.

Pacing needs to be applied to all these activities and your day should include a balanced mix of different sorts of activity.

Rest and relaxation

Short, regular rest periods are essential to recharge your batteries. For your mind and body to benefit, you need to be fully relaxed and properly resting your brain. True rest is needed, and this can be difficult for people who usually relax through active pastimes. Gentle music or relaxation tapes and CDs can be helpful.

Finding a baseline

Before you can start to plan a pacing programme you need to know how much activity you can comfortably manage on a daily basis, without causing an increase in symptoms. This is called your baseline. Baselines sometimes need to start at very low levels and should be manageable, even if you're not having such a good day. To help you become aware of highs and lows of activity (boom and bust) keep a simple diary of your current activities, and how they make you feel.

Remember that working to your baseline does not mean that you have to restrict your life to that level forever, but you do need a stable foundation from which you can begin to build.

Planning and goal setting

Planning your time is essential. You need to prioritise activities and tasks to include those that you have to do, but also those that you enjoy. Once you have established a steady routine you can very gradually, in small steps, build up your activity. This process should take weeks rather than days and you need to approach a goal step by step. It's important to develop awareness of how your body is coping, to sense if you are pushing yourself too hard, or if you have become wary of moving forward.

To find out more about pacing and how to put it into practice, we strongly advise you to download a copy of our booklet *Pacing: a guide for people with M.E.* free from www.actionforme.org.uk or order a copy for a small charge on 0845 123 2380.

Useful contacts

Disability Information and Advice Line services (DIALs)

01302 310 123

Text Phone 01302 310 123 (use voice announcer)

www.dialuk.info

Shaw Trust

01225 716300

Minicom 08457 697288

www.shaw-trust.org.uk

Remploy (agency)

0845 601 5878

www.remploy.co.uk

Prospects (graduate careers advice)

www.prospects.ac.uk

ACAS

Helpline 08457 47 47 47

www.acas.org.uk

Labour Relations Agency (the Agency) – Northern Ireland

028 9032 1442

www.lra.org.uk

Directgov

www.direct.gov.uk

Jobsite

www.jobsite.co.uk

Citizens Advice

www.citizensadvice.org.uk

National Debtline

0808 808 4000

www.nationaldebtline.co.uk**Money Advice Service**

0300 500 5000

Typetalk 18001 0300 500 5000

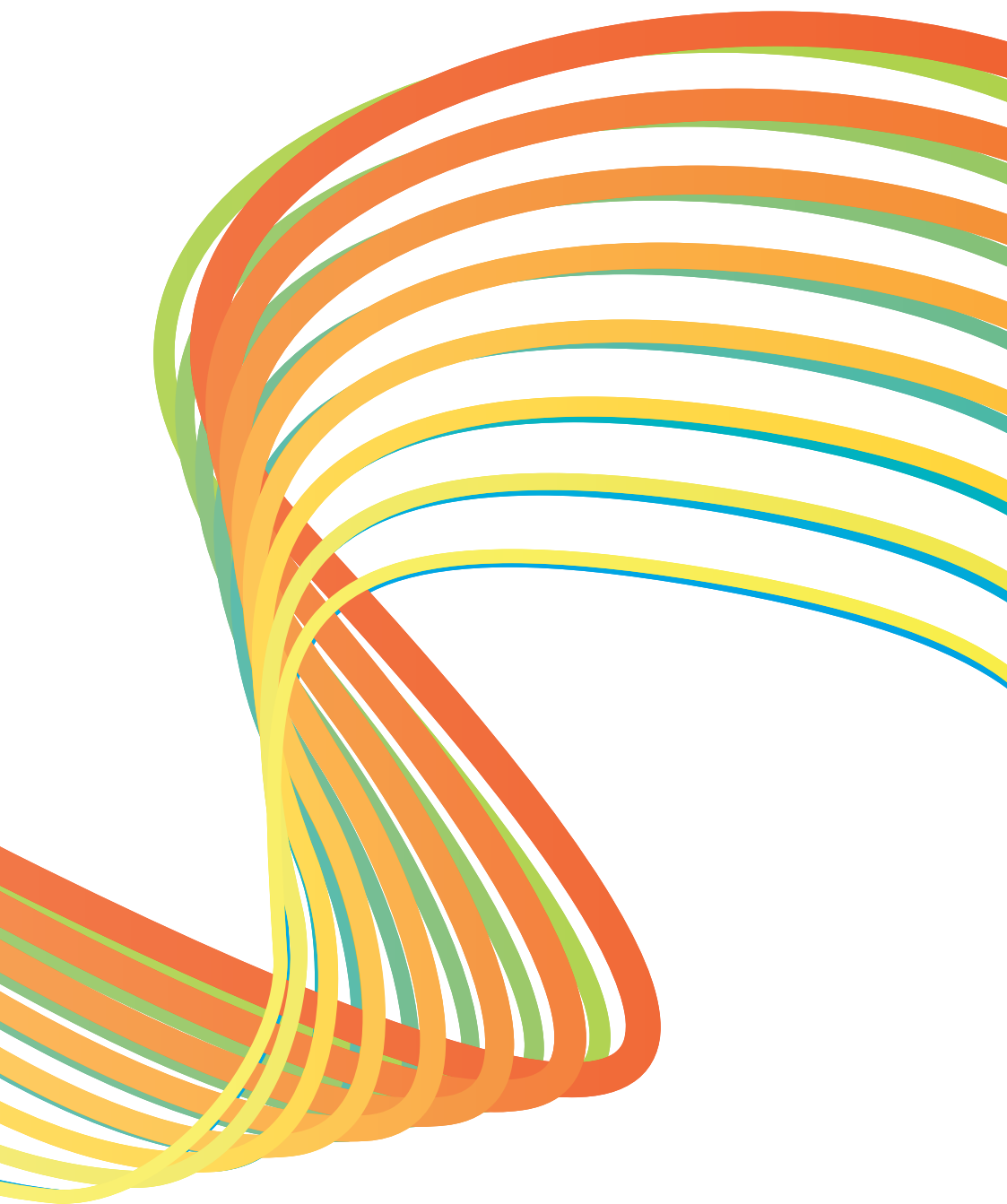
www.moneyadviceservice.org.uk**The Pensions Advisory Service (TPAS)**

0845 601 2923

www.pensionsadvisoryservice.org.uk**Health and Safety Executive (HSE)**

0845 345 0055

www.hse.gov.uk



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