



An employer's guide to M.E.

Information, advice and guidance for managers and
employers supporting an employee with M.E.



Foreword

When you are recruiting or seeking to retain an employee who has M.E. you are likely to have some questions about how you can support and enable them to be the most productive employee that they can be.

M.E. is a complex and fluctuating condition. While some living with the condition are simply too ill to work, others can manage their symptoms effectively enough to successfully work as dedicated, loyal and talented employees.

Bar far the best predictor of a good outcome for all concerned is the use of a collaborative approach that focuses on solutions rather than problems and makes use of all available expertise.

Using this approach, we have seen many cases in which employers have successfully retained valued employees, saved significant associated costs and gained knowledge which will serve them well in future such situations.

The information and advice presented in this booklet is based upon the evidence, experiences and outcomes of SEE M.E., a pilot specialist employment support service for people with M.E., delivered by Action for M.E. in partnership with North Bristol NHS Trust specialist M.E. service throughout 2015 and 2016.



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What is M.E.?

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

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

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

Around a quarter of people with M.E. are severely affected, leaving them house- and/or bed-bound for long periods. Those experiencing this level of symptom severity are unable to work.

Even in its mildest form, M.E. can have a significant impact on an individual's life, and not just on their health. A lack of understanding and awareness about M.E. means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals and employers.

People who have M.E. tell us that they, their employer and the people supporting them need more information about how to effectively manage M.E. at work.

This booklet is for anyone employing or managing someone with mild to moderate M.E. and outlines the employment rights and support available for people with M.E., as well as providing advice on your legal responsibilities, reasonable adjustments, Access to Work, managing sickness absence and sick pay, and recruiting and supporting people with M.E.

Symptoms and their impact on work

Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time.

Post-exertional malaise

Severe and persistent fatigue or exhaustion most, or all of the time, is one of the main symptoms of M.E. This feels very different from ordinary tiredness. Simple physical or mental activities, or combinations of activities, can leave people with M.E. feeling utterly debilitated. They can also experience an increase in other symptoms.

The impact of this may be felt straightaway but it can typically take a day or two to kick in, and is not significantly improved by resting. This is a key feature of the way M.E. affects people, and is known as post-exertional malaise. Harvard University's Dr Anthony Komaroff has described post-exertional malaise as "an illness within an illness."

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 is likely to happen if they have been pushing themselves too hard.

Understanding more about M.E. and the importance of energy management through pacing (see p 8) will help you make reasonable adjustments (see p 17) and provide support in the workplace (p 18).

What causes M.E.?

M.E. can affect anyone of any age or ethnic background, at any time. The causes of the illness are still being investigated. Emerging evidence indicates that there are likely to be a number of factors involved and that there may be a number of different types or sub-groups of the illness.

There is evidence that certain infections can trigger the illness. Many are viruses but M.E. may be triggered in other ways.

Common viral triggers include glandular fever or Epstein-Barr virus (EBV). Other herpes viruses such as herpes simplex, VZV (causes chickenpox/shingles), HHV-6 and CMV, may sometimes trigger M.E., as can viral meningitis or labyrinthitis, commonly caused by enteroviruses, gastroenteritis, Hepatitis A, B and C infection and (in Australia) Ross River virus.

Non-viral triggers include toxoplasma, brucella, salmonella, tuberculosis, Q fever, and Lyme disease. However, there is no clear evidence that M.E. is a form of persistent, chronic infection – it may be a consequence of infection.

There are likely to be a number of factors involved. It sometimes affects more than one family member. The reasons for this are being investigated but some studies indicate that genes can play a part, as can environmental influences.

Symptom management

While there is no pharmaceutical cure for M.E., there are a number of symptom management approaches that some people find useful. Medication can also be prescribed to help alleviate individual symptoms such as pain or sleep difficulties.

Because of the complexity of the illness, its fluctuating nature and the wide spectrum of symptoms, different things work for different people. For those most severely affected, it is often the case that no effective symptom-management strategies can be found, and that employment is simply not possible.

The National Institute for Health and Care Excellence (NICE) guideline for M.E. states that common components of all treatment approaches for M.E. should include advice from a healthcare professional on:

- sleep management
- the role of rest and relaxation.

Treatment approaches should never include:

- an imposed rigid schedule of activity and rest – flexibility is key
- unsupervised or unstructured vigorous exercise – this may worsen symptoms
- specialist approaches delivered by practitioners who have no experience of M.E.

Pacing

Taking control of the balance of activity and rest, and learning how to communicate to others about the balance that usually works best for them, is an approach known as “pacing.”

Action for M.E.’s 2014 *M.E. time to deliver* survey of more than 2,000 people with M.E. found that 67% used pacing to help them manage the symptoms of M.E. Of these, 85% said it was helpful or very helpful (12% said it made no difference, and 4% said it made them a bit or much worse).

Healthy people can usually effectively manage their daily or weekly activities and energy expenditure by building in longer rests after periods of high-energy activities. For example, working hard all week and resting well over the weekends or working hard for four months and having a two week holiday.

People with M.E. who work are unlikely to be able to sustain this, as it does not help to effectively manage symptoms on a day to day basis and can maintain what is known as a “boom and bust cycle,” leading to significant deterioration over time.

With advice from an experienced health professional, M.E.-appropriate pacing should be specific to the individual and involve:

- identifying activities which use energy (these can be physical, mental or emotional)
- establishing a sustainable baseline for regular activities, ie. the level of activity which can be sustained on a regular basis without causing an increase in symptoms
- once the baseline is established, increasing that activity by no more than 10%, until a new sustainable baseline is achieved.

To maintain an M.E.-appropriate pacing programme it can be helpful for your employee with M.E. to:

- tell you and anyone else supporting them personally or professionally about their individual pacing programme and what this means for them
- find new ways of tackling old tasks which allow for a more evenly spread use of energy throughout a day or week
- take short, regular rest periods throughout the day.

Action for M.E. (see useful contacts on p 40) produces printed and online resources with detailed information and advice on pacing.

Understanding your employee's experience of M.E.

Individuals' experience of M.E. varies widely and there is no one single presentation in terms of symptoms, their impacts and the strategies used to cope with them. Your employee will therefore come with their own unique experience of life with M.E.

A diagnosis of M.E. brings uncertainty about symptoms and recovery. This can be a particularly difficult experience and be even more complex in the context of work-related issues that challenge an individual's self-belief and sense of competence.

It is helpful to recognise that the language that a person with M.E. uses to describe their experiences will be unique to them. This will depend partly upon their historic interactions with healthcare services and society more widely, and their personal history and experience of employment and illness.

Many people with M.E. experience a lack of understanding from others and sometimes stigmatising views or discriminatory barriers. So that you can gather the information you need to help successfully recruit or retain an employee who has M.E., you will need to ensure that you create processes and communicate in ways which clearly demonstrate an open and supportive organisational culture. Acceptance and understanding are the keys to successful employment of person who has M.E. and listening and avoidance of assumptions are the routes to this.

"I was not confident to talk to my employer about my condition. I didn't understand my condition myself. I felt that my performance was poor, though my manager never said it was. I was in the depths of despair."
SEE M.E. client

Managing symptoms

When a candidate or employee discloses that they have M.E. it is helpful to ask them what strategies they already use to help them sustain work and manage their symptoms, and then explore how you can support them to use these effectively.

Strategies such as pacing (see p 8) may be used on a wider scale and you may need to gain a broader understanding of them in order to determine how you can best incorporate them into working patterns.

Other strategies may be task-specific or used when certain symptoms are worse. For example, some people who experience brain fog find it helpful to check they have clearly understood a meeting or discussion by confirming their understanding in an email. However, they may worry about how doing so will appear to colleagues. You can reassure them that this is an appropriate strategy and that you understand how it is part of managing their M.E. and work effectively.

“Practical strategies to help manage the cognitive symptoms of M.E. at work are particularly useful. I keep a list of these with me as a reminder.”

SEE M.E. client

Clinical services and support

Research (Pheby and Saffron, 2009) indicates that having a good relationship with their GP from the outset is important when it comes to people with M.E. achieving a good outcome and avoiding severe illness.

However, GPs themselves have identified the challenges they face with regards to diagnosing and treating M.E., and some people with M.E. tell us that they are not receiving the basic care and support that we all expect from our GP.

Action for M.E. works with primary healthcare professionals to address this through training and education.

Specialist NHS services

A number of specialist M.E. clinics exist across the UK, with multi-disciplinary teams usually offering diagnostic services and specialist symptom management programmes. However, coverage is patchy, with several areas not served at all, particularly in Scotland, Wales and Northern Ireland. Accessing appropriate care is, for many, a considerable challenge.

The NICE guideline for M.E. says that referral to a specialist service should be made by a person's GP:

- within six months of presentation for people with mild M.E.
- within three to four months of presentation for people with moderate M.E.
- immediately for people with severe M.E.

Patients who attend a specialist clinic will be individually assessed and then offered symptom management either as individual sessions or within a group.

The general principles of symptom management across specialist services are likely to be broadly similar. Referral to other services may also be required for additional assessment, symptom management or further support and advice. This could include referral to:

- a specialist consultant, physiotherapist, occupational therapist or psychological therapist
- a welfare benefits advisor
- social services for additional care support.

Allied Health Professionals

Occupational therapists (OTs) have specialist expertise in vocational matters and can provide valuable advice to employers (including managers and human resources), work with occupational health teams, and assist employees who have an illness or disability. This can include undertaking and/or advising on:

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

The College of Occupational Therapists (see useful contacts on p 40) can offer assistance in finding an independent occupational therapist

OTs may also, along with other Allied Health Professionals, such as physiotherapists, may be able to provide an Allied Health Professionals Advisory Fitness for Work Report.

This expands upon the Fit Note issued by GPs and is aimed at helping employers and GPs understand practical modifications which may help an employee remain engaged with or return to work.

It is designed to be clearly recognisable and easily read, with contact details for employers to follow up recommendations with practitioners if necessary. The report can be used as stand-alone or additional evidence to supplement GP Fit Notes and to inform Occupational Health assessment.

A template report and related guidance can be found on the Allied Health Professionals Federation website (see useful contacts on p 40).

Your legal responsibilities

Your legal responsibilities to employees with M.E. include:

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

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

Health and Safety at Work Act 1974

The Health and Safety at Work Act 1974 is a piece of legislation which aims to protect the health, safety and welfare of people at work, and essentially requires employers (of any size) to take practical steps to prevent accidents or harm to employees. What exactly is required of an employer will depend on their size and the nature of the business.

The Management of Health and Safety at Work Regulations 1999 makes it clear what is required of employers to manage health and safety, eg. carrying out a risk assessment.

Further to this is Workplace (Health Safety and Welfare) 1992, which gives regulations and guidelines to help employers ensure that the health, safety and welfare needs of employees in the workplace are met. Many of the regulations require that a thing be "suitable" (eg. a chair for working at a computer workstation) for all employees, including disabled people.

What does this mean for you in relation to an employee who has M.E.?

If your employee reports that their work is having an impact on their health, and that some changes could be made to address it, this could be approached as a health and safety at work matter. For example, if poor lighting and air conditioning is causing a person with M.E. noticeably more headaches then these aspects of the working environment could be requested to be improved as a health and safety matter.

If your employer feels that they may be at greater risk of accident or harm at work because of symptoms of M.E. then they have a duty to report this to you as their employer. For example, if a person with M.E. is finding their concentration is impaired whilst they are using potentially dangerous machinery, then clearly this would need to be addressed.

The Health and Safety Executive (see useful contacts on p 40) publishes a comprehensive range of information and guidance on health and safety law requirements.

Stress at work

Health and safety at work regulations place a responsibility upon employers to minimise the risk of stress-related illness or injury to employees. In addition to other impacts of stress, many people with M.E. report that feelings of excessive work-related stress can lead to an exacerbation of their symptoms. We recommend that specialist clinical advice is sought in such cases.

Equality Act 2010

The Equality Act 2010 is a piece of legislation promoting equality and seeking to prevent discrimination on the grounds of any of nine protected characteristics, including disability, which is defined 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. “Long-term” means a condition that has lasted or is likely to last 12 months or more but can include medical conditions that are fluctuating or progressive in nature.

M.E. is understood as a health condition which can have a substantial impact upon a person’s ability to attend work and perform their job. Government guidance relating to the Act lists M.E. and CFS as conditions which could meet the definition of disability. Therefore a person who has M.E. may meet the Equality Act 2010 definition of a disabled person and have rights under the Act.

It is important to note that while an individual, employer, legal or healthcare professional may have a view as to whether a person who has M.E. is likely to be considered a disabled person, only a tribunal court can pass a judgement which actually determines a person's rights under the Act.

Who is covered by the Act?

- Job applicants.
- Workers including casual workers as long as they are not self-employed.
- Contract workers who are employed by another company and supplied to work for a Principal company. The Principal and the employer company have a duty not to discriminate against the contract worker because of their disability.
- A person who is no longer employed so long as the employer's conduct is sufficiently connected with the previous employment relationship. For example where an employer has discriminated against a former employee by providing them with a poor reference.

Your obligations

The Equality Act 2010 places a duty on employers to make 'reasonable adjustments' to help staff overcome disadvantages which result from their M.E., and makes it unlawful:

- to subject an employee to direct disability discrimination. This is where the disabled employee is treated less favourably than employees without their disability. For example an employer does not offer an employee a promotion only because they have ME, where as they would have offered them the promotion had they not had M.E.
- to treat an employee unfavourably because of something arising in consequence of their M.E. For example if an employer dismisses an employee under their absence management policy because the employee has been signed off sick for reasons related to their M.E. Note that the employer can defend such unfavourable treatment if they can show that they it was necessary and proportionate.
- to apply a provision, criteria or practice to the whole workforce which would place a disabled employee at a particular disadvantage in comparison with non-disabled employees. This is known as indirect disability discrimination. The employer can justify the provision, criteria or practice if they can show that it is necessary and proportionate.

- for an employer or another employee to subject an employee to disability related harassment. This is unwanted conduct that has the purpose or effect of violating the person's dignity or creating an intimidating, hostile, degrading, humiliating or offensive environment for them. For example if a member of staff makes derogatory remarks about someone's M.E. condition.

More detailed guidance for employers in relation to the Equality Act 2010 can be found from a number of recognised sources (see useful contacts on p 40) including:

- Equality and Human Rights Commission
- Advisory, Conciliation and Arbitration Service (ACAS, for England, Scotland and Wales)
- Labour Relations Agency (for Northern Ireland).

"I cannot emphasise enough the benefit of having people to talk over the situation with. This particular condition is very stigmatised and misunderstood which leads to added stress and isolation which I believe exacerbates the condition."

SEE M.E. client

Reasonable adjustments

Employers have a duty under the Equality Act 2010 to make “reasonable adjustments” so that employees with M.E. are not placed at a disadvantage (see your legal responsibilities on p 13). The duty is triggered when any provision, criteria or practice applied by the employer or physical feature of their premises places a person with M.E. at a disadvantage in comparison to a person who does not have M.E.

Adjustments can apply to:

- the recruitment process for a job
- where, when and how much a person works
- aspects of the workplace environment
- work duties, how they are carried out and how colleagues work with the disabled person
- support or equipment to enable the disabled person to carry out their job
- policies and procedures used by an employer.

Factors used in determining what is “reasonable” (ie. what a tribunal court will take into account) include:

- how effective the adjustment would be in overcoming the disadvantage
- how possible it is to make the adjustment
- the extent of any disruption to activities/operations
- the nature of the employer’s activities
- the financial and other costs to the employer
- the extent of the employer’s financial and other resources
- the availability of financial and/or other assistance in making the adjustment.

“I was pleased to hear the Human Resources representative talk about the value of my 15 years’ service and how they wanted to retain me, my skills and my experience. I felt really supported and didn’t feel alone with it anymore.”
SEE M.E. client

Effective use of reasonable adjustments

From experience of cases successfully supported throughout the SEE M.E. project, we recommend that a good-practice approach to reasonable adjustments includes:

- understanding the individual's experience of M.E.
- targeting adjustments where symptoms of M.E. are creating specific challenges and disadvantages
- proactively reviewing adjustments on a regular basis
- maintaining a positive, solution-focused approach to this process.

The most effective use of reasonable adjustments occurs when they are based in a good understanding of how M.E. symptoms specifically disadvantage an employee. This is crucial as an individual's experience of M.E. will be unique to them, as are the particular challenges of their work. Coupled with this is the fluctuating nature of M.E. which needs a flexible, longer term approach to managing.

The earlier that adjustments are made, the more targeted they are at an individual employee's needs and the more securely they are maintained, the easier it will be for an employee to remain reliable and productive.

It can often take a period of trialling and modifying adjustments to determine the best fit for the individual, eg. exactly which hours are worked on which days in order to support their pacing plan. With a fluctuating condition comes an expectation that symptoms will improve and worsen at times, so adjustments should be regularly reviewed rather than only when problems have occurred.

Costs and precedents

We understand that many employers are concerned about financial and other costs of making reasonable adjustments, as well as the potential for setting precedents that other employees may wish to make use of.

In our experience gained through delivering the SEE M.E. project, we found that the majority of effective reasonable adjustments came at very little or no cost and that Access to Work funding (see p 22) could often be readily accessed to support purchase of any additional equipment, assistive technology and support. This can include support for making changes to premises where they specifically and only benefit the individual.

Employers are sometimes concerned that by agreeing to reasonable adjustments they may set precedents for other employees. In our experience this tends to be the case only when an employer is coming more from a starting point of “What is going to be reasonable for us to change?” rather than “What is going to be effective for this particular employee?”

This can be clarified to other employees and ultimately helps to promote an open workplace culture which focuses on identifying solutions to health and disability-related barriers to good attendance and performance.

“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

Flexible working

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 their desk, computer or workstation
- attend medical appointments during working hours if required.

Such adjustments can enable a person with M.E. to keep their energy expenditure within their baseline (see p 8), which can be hugely effective in terms of day-to-day reliability, and support improvements in symptoms over the longer term.

You and your employee could consider such adjustments being requested under your Flexible Working policy, which all workers have a right to submit after 26 weeks of continuous employment.

Workload

Discuss workload and how it fits into your employee's pacing programme (see page 8). Reassigning 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 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.

Case example: adapting to a “new normal”

Heather says: *“Upon returning to work I felt like I had been on another planet whilst I was off sick and had returned to a familiar environment but where I am now different.”*

Heather received six sessions of one-to-one coaching funded by Access to Work to assist her to adapt to new ways of working.

“The coaching has helped me to attend more closely and carefully to what is going on, how my body is feeling and to what I need. This can be attending to the little things like making sure I have set up my desk so I’m not constantly moving my head from left to right of the screen and back again. Or making sure I have put files close to hand, so I remember to complete tasks.

“This has enabled me to understand I have a ‘new normal’ and to recognise and embrace this so I can choose how to respond to the requirements of my work and not just react in old, overly fatiguing ways.”

Heather has found this enormously helpful and describes it as building directly upon some of the mindfulness techniques she learnt through clinical treatment at a specialist NHS M.E. service.

Access to Work

Through SEE M.E. we found that Access to Work (see useful contacts on p X) made a crucial difference to people with M.E., enabling them to manage their condition more effectively at work.

We recommend that employers make their employees who have M.E. aware of Access to Work at the earliest opportunity and support them to make the most of what it can offer to both employer and employee.

Access to Work provides practical advice and financial support to help overcome the barriers to work experienced by disabled people and people who have long term health conditions. Someone with M.E. can apply directly to Access to Work when:

- you have offered a job and they have disclosed their M.E. to you
- they disclose their M.E. as a new employee and you assess what adjustments and support is needed
- they are an existing employee who has just been diagnosed with M.E.
- they are an existing employee who is returning to work after a period of absence due to M.E. and you are planning what can effectively support their successful return
- they are self-employed or running a small business and are contracted to provide services to you.

Through a process of advice and assessment, Access to Work can provide an individually-tailored funding package to enable an individual and their employer to purchase:

- specialist aids, equipment and assistive technology
- adaptations to existing equipment
- travel to work or in work
- support workers
- training and coaching.

Access to Work will fund only support which is considered over and above that which is reasonable for an employer to provide. It does not replace an employer's duty to make reasonable adjustments and may recommend support or equipment which it part-funds and expects the employer to also contribute to.

As with reasonable adjustments, funding equipment and support objective through Access to Work aims to reduce unnecessary energy expenditure so that it can be focused on that which is really important.

Bringing in equipment and support can also help to adapt the approach taken to specific tasks so that they can be undertaken more quickly and efficiently and/or sustained for longer periods.

As a specialist workplace assessment is a common part of the Access to Work assessment process, it is not necessary to have a clear idea of what Access to Work may recommend ahead of applying.

What can Access to Work fund?

Real examples of Access to Work funding for SEE M.E. clients with M.E. have included:

- noise cancelling headphones to support improved concentration in a busy office environment
- ergonomic chair to promote “active sitting” and thereby reduce fatigue caused by static sitting and accumulated pressure on joints and associated muscle groups
- forearm supports, which clamp on to the person’s computer desk and provide moveable support to reduce fatigue and joint pressure
- post trolley to help a person with M.E. transport heavy or cumbersome items, thus reducing associated fatigue and risk of injury
- text-to-speech software for reading long documents aloud, supporting improved absorption and retention of information
- speech-to-text software to enable easier recording of thoughts and production of longer typed pieces of work
- mind-mapping software to help support planning and strategic decision-making
- taxis to and/or from work, reducing fatigue that was being exacerbating by public transport commute
- job aide, employed to help a teacher set up and clear away classroom activities, reducing fatigue associated with this more physical aspect of their job
- six one-hour coaching sessions over a period of time, to assist a person with M.E. to adapt and develop new ways of working in their job.

Case example: how assistive software helped overcome brain fog

As a senior university lecturer, Heather has to mark large quantities of student course work and exam papers. The cognitive difficulties (often referred to as brain fog) she experiences make this difficult. Heather can find it hard to fully absorb what she is reading and in the few moments it takes her to look away from the paper to type her marking comments, she can lose her train of thought.

Through Access to Work Heather received screen-reader and speech-to-text software, plus one-to-one training in how to use them within her specific job tasks. Now Heather can listen to student's work read through her computer and speak her comments aloud, which are automatically typed. She says,

"I can process what I hear more easily than when reading papers and can capture my thoughts before they vanish. The whole process is now quicker and less fatiguing."

Sickness absence

When an employee is genuinely experiencing difficulties in carrying out their job because of their symptoms or frequent bouts of sickness absence, this as 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 through can be counter-productive and damaging, potentially causing longer absences.

If you take a flexible and supportive approach, listen to your employee as they learn about their condition, make reasonable adjustments and support an M.E.-appropriate return to work, then it is far more likely that your employee will be able to continue working.

Fit for Work service

Fit for Work (see useful contacts on p 40) is a free, impartial, government-funded initiative designed to support people who are off sick from work, their employer and GP. The aim is to inform the processes you have for managing sickness absence and employees who have a long-term health condition or are disabled.

If you have an employee who has been (or is expected to be) off sick from work for more than four weeks, you can refer them for a voluntary assessment with an occupational health professional.

Returning to work

When a person is signed off sick from their current job it can sometimes be hard to imagine how returning to work might be possible. Many employees will follow their employer's lead and may not feel that they can be proactive in suggesting solutions that can help them sustainably manage their return.

Planning to return to work should be a process of negotiating well-informed decisions based on what is believed will be most likely to succeed for an individual, rather than being determined by a one-size-fits-all policy.

Getting the timing right

When supporting a person with M.E. to start planning their return to work it can be difficult to get the timing right: too early and it can feel overwhelming, but leaving it too late can increase uncertainties and anxieties for all concerned.

We have found that encouraging them to consider how they might return to work early on helped maintain a positive dialogue between the employer and employee – as long as a longer term, realistic view of the process is maintained.

Concrete solutions help to bridge the path back to work and build employer and employee confidence that it will be effective and sustainable. It is important to remind your employee that agreed plans are only a starting point to be reviewed regularly and adjusted if needed.

If further absence is needed

If your employee has been signed off sick for a further period and is not yet able to consider a return yet, then keeping in touch is of course good practice. Keep in mind that a reduction in your employee's self-belief may undermine their confidence to return. So do remain optimistic and supportive throughout.

If your employee has made repeated attempts at a phased return to work, but these continue to fail, then you will need to consider whether your expectations or those of the employee (or other colleagues) are too high. It is important to ensure that you have taken on board all possible external input in the form of information, advice, recommendations and resources before progressing the case.

Sometimes, despite making best use of the support available to them, some people with M.E. are simply not well enough to manage a return to work. See p 32 for information about supporting your employee with M.E. to leave work well.

Returning to work

Fitness for work is not an all-or-nothing thing. An effective return-to-work plan builds up gradually in terms of hours worked and duties undertaken, as well as testing out any reasonable adjustments. This plan helps someone with M.E. work within their baseline and to slowly increase in accordance with any pacing or graded activity plan.

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

- clinical advice – see below
- an M.E.-appropriate return to work – see p 28
- flexible working arrangements (those that all, including non-disabled employees have a right to request) – see p 19
- reasonable adjustments – see p 17
- Access to Work – see p 22
- how it will be reviewed and sustained in the longer term – see p 30
- confidentiality and communicating with colleagues – see p 31.

Clinical advice

Employees will feel considerably more confident to attempt a return to work when it has been planned in line with the clinical advice that they have been given. A fear of not being reliable or of relapse can undermine even the best made plans, so taking full account of specialist clinical advice, at the right time, is important.

If your employee is accessing a specialist M.E. clinical service, then seek consent to request a report from them and incorporate this into your decision making processes.

“From our perspective offering [our employee] with M.E. an extended phased return [period] was felt to be an investment, allowing [her] the time and support to regain confidence and capability in a role in which her knowledge and skills are seen as invaluable. As an organisation we are committed to supporting attendance; negotiating with [our employee] to facilitate a return based on her needs and the needs of the service meant we could focus on enabling attendance rather than considering a premature retirement from work.” Manager of employee with M.E.

An M.E.-appropriate return to work

A phased return to work is a commonly used approach to supporting employees who have been off sick from work. It is a period over which working hours are built up towards the fully contracted number, while in receipt of full salary. Many employers have a policy which state the maximum permitted length of phased return period, often six weeks.

However, returning to work after a period of absence due to M.E. may require a much more gradual approach in order to be successful. A longer staged return to work period could include:

- a reasonable adjustment to the phased return policy which recognises that an effective adjustment for a person with M.E. is a longer period over which to increase hours
- use of annual leave
- a temporary variation in the contract to reduce the hours that are being increased towards (and therefore also salary for the period).

The return-to-work plan then provides a clear supportive framework to the phased return. The following should be considered within a phased return period:

- building up work or work-related skills at home at first
- planning in some home-working days when they have started to return to the workplace itself, not just before
- phasing in workload or targets as well as hours to help build confidence about what is manageable. Bear in mind that 50% of workload or targets to be achieved in 50% of the time may be relatively harder and potentially stressful
- allowing for regular breaks and perhaps a longer lunch to build in rest periods which are in an appropriate place. A properly restful lunch break, somewhere comfortable, quiet and undisturbed, can make a great deal of difference.

Case example: a successful return-to-work plan specific to individual needs

“SEE M.E. helped me negotiate a much extended phased return to work which, I believe, has made the crucial difference between me getting back to work and not. My employer initially proposed a six-week phased return period, which was increased to 12 weeks as a reasonable adjustment that was targeted at my specific condition-related needs, plus a further six weeks through the use of annual leave. SEE M.E. was instrumental in helping me plan my return to work and consider how to work this into my energy and symptom management.

“The last few weeks have been harder so my confidence about sustaining my work is a bit less at present. However, SEE M.E. has continued to support me in this and has reminded me that the nature of M.E. means that there will be up and down times. I think this helped normalise this experience for me and helps me keep it in perspective.”

Expecting changes

The nature of M.E. as a fluctuating, long-term health condition means that there are likely to be changes in presence and severity of symptoms, which in itself adds an additional challenge to sustaining work. After the initial set up of reasonable adjustments and once the person with M.E. has settled into their new routine there are sometimes factors that have the potential to derail the success of the process. For example, temporary workload increases, demands from home-life, a change of manager or operational changes. In the longer term an additional factor can be that all parties become more comfortable and forget the need to maintain helpful strategies. Additionally a person with M.E. may not feel comfortable repeatedly asserting the need to maintain boundaries and adjustments as they don't want to appear as though they are not committed to their work or colleagues.

For example, it can sometimes be challenging for a person with M.E. to maintain their pacing on days at work when they feel a bit better. Instead they might try to 'make up' for the bad days without realising they are doing too much. Regular reviews and open communication between the employer and employee is crucial and a workplace mentor can help the individual reflect on how they are managing to maintain their strategies.

Regular reviews

Given the expectation of fluctuations and the need to be flexible, it will be helpful to schedule regular reviews, rather than only meeting to address problems that may occur. We recommend incorporating reviews into regular employee one-to-one processes in a proactive and supportive manner. This approach is more sustainable, less time-consuming and less costly for employers than reviews triggered by absence or poor performance.

Good practice reviews will include consideration of:

- the extent to which previously agreed plans and adjustments have been fully implemented
- the extent to which adjustments and ways of working have been effective in enabling your employee to overcome challenges and disadvantages
- how your employee is managing to combine their clinically informed condition-management strategies with workplace policies and processes
- what changes to existing plans or adjustments may help
- what further information, advice, adjustments or support may help
- what additional resources or expertise could be accessed to support any further changes needed.

"This is the worst time of year for me and I am horrendously tired. I now know I need to manage the condition and can spot the boom and bust. I know I need to continue to make adjustments at work and at home. Before, I was in denial and this wasn't helping my work situation."

SEE M.E. client

Confidentiality and communication

It is advisable to ensure that any key points agreed are recorded in writing, so that they can be referred back to later. This is especially helpful if your employee experiences cognitive difficulties (such as with concentration or memory). It is of course especially important to have a written record of any changes which impact on their job role, salary or other terms and conditions of employment.

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 employee's M.E. should not be shared with any other person, inside or outside the organisation, without their prior expressed consent.

However, maintaining good communication with colleagues is also important in terms of professionalism and good will. Colleagues may be genuinely concerned for an employee who is returning to work after a lengthy period of absence, and some adjustments that have been agreed may have an impact upon them too. We therefore recommend discussing with your employee what needs to be communicated when and to whom, in order to encourage an understanding and supportive response from the wider team.

If a return to work isn't possible

Despite practicing pacing (see p 8) and deploying self-management skills learnt in specialist clinics, some people with M.E. continue to deteriorate and are not be able to return to employment.

If a workable solution cannot be found to ensure your employee's continued employment and/or return to work, you can support your employee to leave work in a positive way by putting a best exit plan (see below) in place.

Options include:

- offering early retirement or voluntary redundancy, with pay in lieu of notice
- offering re-employment at a later date if your employee improves sufficiently, or a career break if your organisation's policies allow them
- if appropriate, reassuring your employee that you will provide a positive reference in relation to their performance at work.

Dismissal on grounds of capability

An employee may be dismissed on the grounds of capability if they are unable to do the job they were employed to do. However, this should be a last resort after following your relevant organisational policies and procedures (ie. capability and/or absence management).

After putting in place reasonable adjustments and exhausting options for support, it may still be fair to dismiss an employee with M.E. on the grounds that they are no longer able to do their job effectively. This should be done in consultation with your employee and after seeking appropriate legal advice (see useful contacts on p 40).

Ill-health retirement

Your employee may belong to a pension scheme that allows early retirement due to ill health. The pension provider will require formal medical evidence to be submitted, which clarifies the effect of their health condition/symptoms on their ability to carry out their job. This may be a medical assessment with a representative of the pension provider, or the evidence might be submitted by your organisation's occupational health provider. Some pension providers offer different tiers of ill-health retirement, so it may be that your employee can't continue in their current role but may be well enough in the future to carry out a different role.

As an employer you can support your employee to consider this option and help them access any relevant advice through your pension provider. You may also be required to provide supporting evidence about your employee's capacity to stay in their current role.

Best exit

It is important that, if your employee has to leave, they do so in a positive way and have the best possible exit from work. This is not only about finding the most appropriate option, but also about them feeling that they have not left under a cloud. For example, you could offer them the opportunity to come back into the workplace and say goodbye to colleagues if they feel that is what they want to do. Some organisations have support services in place for those who have left: might your employee be eligible for this?

Sick pay and benefits

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

If decisions are being made about how many hours your employee is able to sustain when returning to work for after a period of sickness then understanding their eligibility for certain welfare benefits may be very important for them. For example, it may enable you to retain an experienced employee on reduced hours, if they feel better able to do this due to receipt of in-work welfare benefits.

Statutory Sick Pay

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 employers for up to 28 weeks in any period of sickness lasting for four or more days.

It is primarily an employer's responsibility and the scheme is operated by HM Revenue and Customs (HMRC). Detailed information can be found in the *E14 employer helpbook* for statutory sick pay which is available from HMRC (see useful contacts on p 40).

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.

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.

Welfare benefits

We know from experience that many people with M.E. and their employers are unaware of the full range of welfare benefits available to them. This is especially so for people who are in employment and where additional welfare benefits income may be just what they need to continue working while scaling back hours worked to a more sustainable level.

- Personal Independence Payment is a non-means tested benefit designed to help with the extra costs of living with a long term health condition. There are two components to it – mobility (getting around) and daily living activities.
- Employment and Support Allowance (ESA) can be claimed by people who have a contract of employment and are off sick from work but no longer entitled to SSP.
- People who are working but on a low income may be entitled to Working Tax Credit if they are working at least 16 hours per week (and in some cases 30).
- ESA and Working Tax Credits (along with Jobseekers Allowance) are nationally being phased out and replaced by Universal Credit, under which eligible criteria and other regulations may differ.
- Universal Credit is a single monthly payment for people who are in or out of work, which merges together some current benefits and tax credits. It is being rolled out in stages across the country and across the different benefit types that it is replacing.

Action for M.E.'s Welfare Advice and Support Service (see useful contacts on p 40) offers free confidential advice and information about welfare benefits to anyone affected by M.E.

We also have a number of detailed factsheets relating to welfare benefits that can be read and/or downloaded at www.actionforme.org.uk (or paper copies ordered by phone).

Recruiting someone with M.E.

If you are considering offering employment to someone with M.E., you may have some practical questions.

As M.E. is a fluctuating condition, there is no single presentation in terms of symptoms, their impact and the strategies used to manage them. Potential employees will come with their own unique experience of life with M.E., so it is important to gain a good understanding of this through appropriate discussion with them. You may also be able to request, with the individual's consent, a letter or report from their specialist M.E. clinician.

From our experience of delivering the SEE M.E. project, we know that appropriate reasonable adjustments and symptom management strategies recommended by their clinician can support a person with M.E. to successfully and reliably sustain the right kind of work, if they are well enough to do so.

Adjustments to consider within your recruitment procedures include:

- flexibility around interview times and dates to accommodate health appointments
- how the candidate will reach the interview venue; if public transport could prove difficult, offer to reimburse a taxi fare or provide close car parking
- ensuring that your interview is held in an accessible location, eg. on the ground floor or in a room accessed by a lift
- ensuring that your interview environment is free from excessive noise, light or other possible disturbances
- building rest breaks into longer interview/assessment procedures
- permitting use of prepared notes to aid the candidate's memory when giving answers to competency-type interview questions.

Health-related questions

Under most circumstances, employers may not normally ask health-related questions of a job applicant until after a job offer has been made. The most common exception to this is to determine what, if any, reasonable adjustments need to be made to your selection process (eg. the interview).

A person can complain to the Equality and Human Rights Commission (EHRC) and/or seek advice and support from a local Law Centre if they think you are asking questions unlawfully. The EHRC (see useful contacts on p 40) 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

Once you have conditionally offered a person a job, the Equality Act 2010 permits you to ask appropriate health-related questions.

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

Support and advice

Contact details for the following sources of support and advice are listed on p 40.

Jobcentre Plus offers employers general advice and specific case support to assist you in recruiting a person with M.E. Your local Jobcentre Plus office can put you in touch with a specialist in health and disability recruitment, who may also be able to signpost you to other local services.

Business Disability Forum provides support and advice, including sharing practices which employers and disabled people have found effective.

If you are unsure or concerned about your legal responsibilities, contact ACAS (in England, Scotland and Wales) or the Labour Relations Agency (in Northern Ireland).

Help with any additional costs associated with making reasonable adjustments for a new employee who has M.E., may be available through the Access to Work programme – see page 22.

How other employers support their staff

Here we present case studies that further demonstrate some of the effective practices which have made a real difference to the outcomes for both employer and employee.

If you are an employer who has supported someone with M.E., or an employee who has benefitted from such support, please contact Action for M.E. (see p 40) that we can highlight this good practice in our communications.

Case study: Fran

Fran was first diagnosed with M.E. 20 years ago. She went to see her M.E. specialist because of a relapse during 2014. She had been off work for a year. After the first six months of absence, her employer asked for a return-to-work date. They were being supportive but because of the fluctuating nature of her condition, Fran was finding it difficult to commit to a return date, and this wasn't helped by having four different managers over the period, not all of whom knew her well.

Fran says, "The whole idea of managing to go back to work was terrifying because I just couldn't concentrate. I was terrified that I would go backwards and have my contract terminated on the grounds of ill health."

Fran was referred by her clinician to the SEE M.E. service, which was able to access the letters written by Fran's clinician and discuss this with them.

"I felt that I had to give it a go and SEE M.E. helped me negotiate an 18-week return to work (including taking annual leave), rather than the usual six-weeks' normal phased return.

SEE M.E. helped Fran to set some employment goals that weren't just about getting back to work but about returning to work in a sustainable way. SEE M.E. supported Fran with her Access to Work assessment which led to some very practical measures being put in place including a mail trolley and noise-cancelling headphones.

The SEE M.E. Employment Adviser said, “The key was negotiating an extended phased return period. Where employers have a policy around phased return they can often get stuck trying to apply it rigidly. However, slower staged phased return via an adjustment to their phased return policy can be a reasonable and effective recognition of the persons needs due to their condition.

“The employer was open to trying things and prepared to really listen to the clinical advice. The employer was very committed and determined to come up with a plan that would work for the employee”.

Fran reports: “I started back in November. It is hard work but I am coping. I was really unsure that I could do it. The extended phased return period was what really made the difference.”

Case study: 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 has been very important and space has always been made available for me to do this. Even during the worse stages of my illness, my employer has always made me feel that I was still a valuable member of the team. I have found the support from management and my work mates to be extremely valuable ‘therapy’.”

Useful contacts

ACAS

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

Tel: 0300 123 1100

www.acas.org.uk

Access to Work

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

Tel: 0345 268 8489

www.gov.uk/access-to-work

Action for M.E.

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

Tel: 0117 927 9551

Email: admin@actionforme.org.uk

www.actionforme.org.uk

Action for M.E. Welfare Advice and Support Service

For specialist information and advice regarding welfare benefits

Tel: 0800 138 6544 (call for opening times)

Email: welfare@actionforme.org.uk

Allied Health Professionals Federation

Promotes inter-professional working and high-quality care for patients and carers across health and social care sectors

Tel: 020 7378 3022

www.ahpf.org.uk

Business Disability Forum

Shares expertise and advice, provides training and facilitates networking opportunities

Tel: 020 7403 3020

www.businessdisabilityforum.org.uk

College of Occupational Therapists

Online directory of reputable independent occupational therapists

Tel: 0845 129 7699

www.cotss-ip.org.uk

Equality and Human Rights Commission

Independent statutory body encouraging equality and diversity in Britain

England: 0845 604 6610

Scotland: 0845 604 5510

Wales: 0845 604 8810

www.equalityhumanrights.com

Fit for Work

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

Tel: 0800 032 6235

www.fitforwork.org

Health and Safety Executive

Aims to reduce work-related injury and ill health

Tel: 0845 345 0055

www.hse.gov.uk

Jobcentre Plus

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

Tel: 0345 604 3719

www.gov.uk/contact-jobcentre-plus

Labour Relations Agency (NI)

Information and advice on employment-related disputes in Northern Ireland

Tel: 028 9032 1442

www.lra.org.uk

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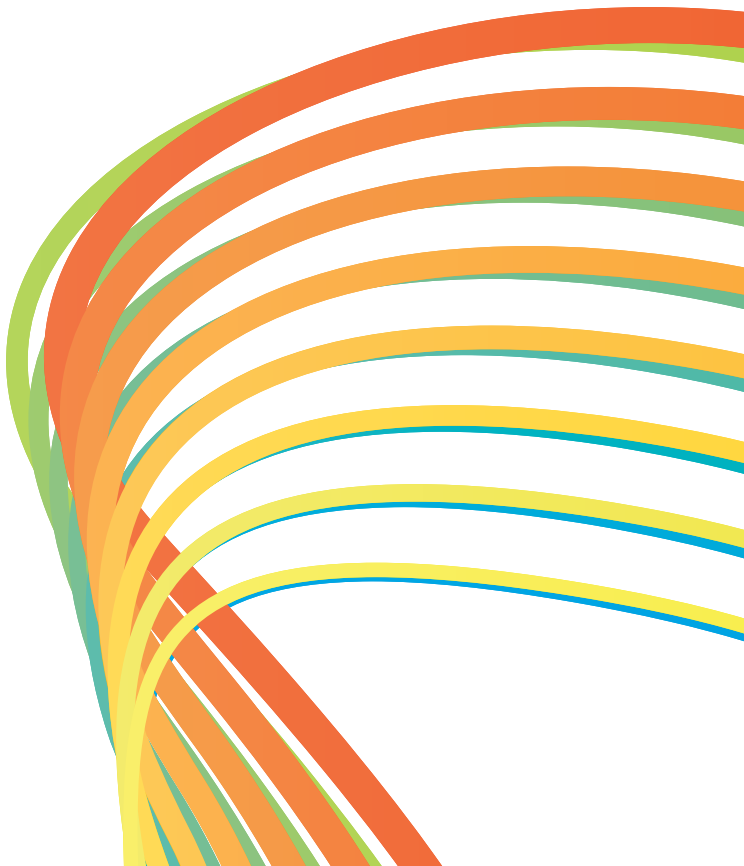
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Action for M.E. takes action to end the ignorance, injustice and neglect experienced by people with M.E. We provide information, support and advice to people affected by M.E. to help improve their health and well-being. We work with professionals to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



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