



Support, empower and employ people with M.E.

A toolkit for professionals



Contents

Introduction

Using the toolkit	4
A note on terminology	4

Essential knowledge and approaches

What is M.E.?	5
Your client's personal experience	5
The importance of an individualised assessment	6
Supporting belief in self-management strategies	6
A word on "disability"	6

Integrating support

The impact of distance between services	8
The impact of uncertainty	8
Easing the burden of action	8

Enabling interventions

Planning for M.E.-appropriate work	10
Key principles for planning future employment	11

Disclosing M.E. to an employer

Telling an employer	13
Who to tell and what to tell them	13
How to tell them	14
What information should your client share?	14

The solution-focused approach

Challenges, needs and solutions	12
---------------------------------	----

Flexible working and contractual variations

The right to request flexible working	15
Redeployment	15
Temporary reduction of hours	16
Career break or unpaid leave	16

Reasonable adjustments

What can be adjusted and what is reasonable?	17
What makes adjustments effective?	18
Reviewing adjustments	18
Clear communication	19
Addressing employer concerns	19

Access to Work

What can Access to Work fund?	21
-------------------------------	----

Return-to-work planning

Getting the timing right	22
An M.E.-appropriate phased return to work	22
Confidentiality	23
Communication with colleagues	24
For clinicians: producing reports and letters	25
Fitness for work reports	25

Sustaining work

Expecting changes	26
Planning for fluctuations	26

Legal considerations

The Equality Act 2010 and M.E.	28
What does the Act do?	28
What does this really mean?	29
Health and Safety at Work Act 1974	30
Stress at work	30
In-work welfare advice	31

Resources

Resource one: Key things to remember	32
Resource two: Individual needs assessment	34
Resource three: Sources of information and advice	36
Resource four: Challenges, needs and solutions worksheet	38

Acknowledgements

	39
--	----

Introduction

Many people with the chronic neurological condition M.E. want to work and are highly motivated to seek, return to and sustain employment. However, too many people with M.E. experience a lack of understanding about M.E. and its impact, and too great a distance and disconnection between the services offering them support.

In response to this need, Action for M.E. delivered Support, Empower and Employ M.E. (SEE M.E.), a pilot specialist employment support service for people with M.E. living in Bristol and the surrounding regions, from 2015 to 2016. This was embedded within Bristol NHS specialist M.E. service and integrated with local employment support services.

The information and advice presented in this toolkit is based upon the evidence, experiences and outcomes of the SEE M.E. service, and aims to improve employment outcomes for people with M.E. by informing the practice of those professionals working with them.

Using the toolkit

The toolkit will be particularly useful for specialist M.E. clinicians, employment advisers, work coaches and careers guidance practitioners, but professionals working in social care, welfare advice and trades unions may also find it useful.

It is designed to provide information, good practice advice, real case examples and practical resources, to enhance your ways of working with patients, clients and customers. It is not intended as a comprehensive guide to everything related to M.E. and work, and the use of the toolkit should be discussed within your organisation to determine how it can best be incorporated.

This toolkit is presented as a series of topics for discussion and exploration, informed by the most common issues presented at our SEE M.E. service. Each section presents information and our experience of working with people who have M.E., and recommendations on ways of working, including specific interventions (in green boxes) and resources (in blue boxes). Case examples and client feedback (in yellow boxes) illustrate the value of our recommended approaches throughout.

It is important to understand that the guidance given in this toolkit will not automatically result in your client with M.E. being able to sustain or return to employment. Despite practicing pacing (see opposite) and deploying self-management skills shared by specialist clinicians, some people with M.E. are simply too ill to return to employment.

A note on terminology

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 toolkit.

We use the term 'work coach' to mean anyone involved in providing personalised employment-related support, such as personal advisors, employment advisers and careers guidance practitioners.

We use the term 'clinician' to mean any healthcare professional working with anyone with M.E. who has employment needs; this may be a GP, occupational health professional, specialist M.E. consultant or physiotherapist.

We use the term 'client' to mean your customer, patient or any other term you may use to refer to a person you are working with in your professional capacity.

Essential knowledge and approaches

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.

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. Research (Nacul et al, 2011) shows that, in terms of mental and physical function, M.E. is significantly more disabling than most other chronic health conditions, including lung disease, depression, heart disease and diabetes.

Individuals with M.E. can vary enormously in their experience of the illness, and there is no universal presentation in terms of symptoms and their impact. Some make good progress and may recover, while others can remain ill for a number of years and may not get better. Some people don't go back completely to the way they felt before they became ill, but they do recover sufficiently to lead happy and fulfilling lives. This is similar to other chronic illnesses.

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

People with M.E. use a number of approaches to self-manage symptoms, including a structured way of balancing activity and rest known as pacing. Patient surveys repeatedly report pacing to be the most popular symptom-management approach used by people with M.E., and its key principles are:

- establish a baseline (the level at which you can maintain a particular activity on both a good and a bad day)
- increase activity from this established baseline by no more than 10%.

However, it's important to note that pacing is not a cure – there is no pharmacological cure for M.E. It is also important to note that, for the most severely affected, it is often the case that no effective symptom-management strategies can be found.

Your client's personal experience of life with M.E.

A diagnosis of M.E. often brings a degree of uncertainty about symptoms and recovery. This can be particularly difficult and become even more complex in the context of employment 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 experience will be unique to them. This will depend upon historical interactions with healthcare services and society more widely, as well as their personal history and experience of employment and illness.

The fluctuating nature of M.E., in severity of symptoms and the capacity to function, creates a significant challenge in terms of maintaining strategies that best support day-to-day coping and longer term recovery. It is understandable that when a person with M.E. experiences an improvement in symptoms they are likely to increase their level of activity accordingly.

This may include a combination of attending to life's absolute necessities and some time spent in an enjoyable activity – both are important for the person's sense of independence and well-being. However, post-exertional malaise (see above) means that the impact of any activity may not be felt straight away.

In order to support a person with M.E. towards their employment goals it is important to understand that an individual's experience of the condition is a very personal one. For example, one person who appears to be managing well may be delicately balancing a variety of coping mechanisms in order to successfully manage their situation. It does not necessarily follow that they have capacity to make changes or take on new actions.

Another person with M.E. who is reluctant to take on more activity may have previously experienced bad set-backs and relapses in the past. However, with the right clinical guidance and practical workplace adjustments, they may have capacity to sustain a little more, should they choose to do so.

It is important for work coaches to work with clients to identify practical strategies (with clinical input where possible) that enable them to safely undertake activities – and not to encourage them to keep going with activities until they feel too tired. Your client with M.E. is the best expert on their condition.

"It is easy to find 'sympathy' but much harder to find solid advice and knowledgeable support to help with resolving M.E.-related employment issues." SEE M.E. client

The importance of an individualised assessment

It is crucial not to make assumptions about a client's experience of M.E. and how they are managing it. Take time to listen to and really understand your client's unique personal experience. Investing time into this individualised assessment approach is essential to building the trust and rapport you need to provide effective support.

"[What helped the most was] feeling I'm not alone with this condition, being listened to and learning to put strategies into place to support my condition." SEE M.E. client

Supporting self-management strategies

To grow in self-belief and confidence to achieve their employment goal in the face of the uncertainties, stigma and discrimination that can surround M.E., your client will benefit from your support to build awareness of how they can tackle and manage specific work-related challenges.

Many of the people who accessed our SEE M.E. service described the importance of being heard and believed alongside learning practical strategies to manage their condition in work. This helped to support growth in self-confidence and belief in their ability to manage their employment situation more assertively and effectively.

For example, volunteering can provide an ideal testing ground for people with M.E. to learn specific strategies for managing the work itself and day-to-day/week-to-week life in order to sustain activity and increase reliability.

"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. It is very likely I would not have gained employment without the support of this service. It has helped me think clearly and rationally about what I need to do and taken me away from blurry and emotional decision-making. As a result I am calmer and more confident." SEE M.E. client

Some clients you see may have just received a diagnosis of M.E., or are waiting to have this diagnosis confirmed by a specialist. You can let them know that Action for M.E.'s *Newly diagnosed with M.E./CFS* resource, which is endorsed by the National Institute for Health and Care Excellence December 2015, offers targeted information, advice and signposting, including guidance to help them be an active partner in their own care.

A word on "disability"

Commonly encountered definitions of disability can often appear black and white (eg. attending an assessment which decides whether or not a person is entitled to a service or benefit as a disabled person). This informs common attitudes towards disability in society.

Fluctuating health conditions often do not so neatly fit into this model and this can have an impact upon how people with M.E. view themselves in relation to their rights, entitlements and support available to them.

A person with M.E. who has better days during which they can consider working may well find it quite challenging to accept a label of "disabled." This should be understood in the context of the resolute and positive attitude that must be taken to manage day-to-day life with M.E. and pursue longer term recovery.

Many SEE M.E. clients told us that they refuse to see themselves as disabled. They described feeling like "a bit of a fraud" when they have occasional really good days, even though they know there are also horribly bad days.

As we will explore throughout this toolkit, there are important legislated rights, statutory services and entitlements as well as supportive approaches by employers that can hinge on the use of this label. It will be important to explore with your client how they can make use of these to support themselves to move forwards towards their employment aspirations. To do so effectively may require you to spend some time understanding and working with your client's personal views around the label of "disability" and any experiences of stigma and discrimination.

Interventions

- Take an approach which demonstrates through questions and reflections, not assertions or assumptions, that you are listening to your client's unique experience of M.E.
- Build trust and your own understanding by admitting what you don't know about M.E. and not being afraid to ask your client about their experience in detail.
- Ask about the coping strategies and symptom-management techniques that your client uses and work together to incorporate them into any action planning.
- Ensure that you take careful note of your client's preferred language about M.E. and briefly remind yourself of this before each meeting.
- Where you perceive a barrier to your client's desired direction of progress, discuss and explore it through gentle enquiry, openly describing them as the best expert on themselves.

Resources

- See *Key things to remember* (p 32) for an overview of the process of working with someone with M.E.
- See our *Individual needs assessment* worksheet (p 34), all or parts of which you can incorporate into your existing work.



Integrating support

The impact of distance between services

People with M.E. told us that the services available to them, especially employment and healthcare services, were too disconnected and that the distance between them could prevent them from accessing the advice and support they needed when they needed it. People with M.E. told us this was one of the main factors which undermined their ability to gain or retain work.

The impact of uncertainty

"Sometimes you feel being off work is a job in itself. We had two meetings about a return to work. [SEE M.E.] were present and prior we had met to go through the options and how it could look and liaised together with my specialist at the clinic. There was also input from occupational health and my union. It was good to have that all linked together." SEE M.E. client

When an employee is off sick from work because of a well-understood health issue, a clear prognosis for recovery is often possible and the time needed off work is more likely to be understood and managed by the employer.

Conversely, when an employee is unable to work due to M.E. they will have an uncertain prognosis and unclear future fitness for work. Often employers will not receive the kind of medical information they need in order to make clear-cut decisions and which their internal policies may call for. The uncertainty and anxiety that this can cause for employee and employer can undermine the determination to support the employee to do what they need and return when they can.

As already explored, uncertainties about M.E. can also undermine your client's confidence and self-belief to work or seek employment, and also to engage with the services available to support them to do so.

Easing the burden of action

"It was a huge learning curve for me around M.E. I had an idea of what it was but I didn't know about prognosis or baseline and activity levels and working. It was very interesting. If I come across anybody else in this situation the knowledge I have gained will be really useful." Trade union representative for SEE M.E. client

A range of specialist expertise, in addition to the GP, can be called upon when a person is employed but off sick from work; including occupational health, specialist clinicians, Access to Work and health/disability employment support services. However, engagement with this expertise can add further demands on your client. An imminent risk of job loss brings the need to seek further sources of advice on welfare benefits, pensions and employment rights. This can create a further burden of travel, action, learning and decision making.

Hence it is vital for services working with clients with M.E. to facilitate access to other services, while also paying attention to what they say they can actually manage to do (rather than would ideally do).

This includes increasing active professional liaison with other services, which can make a significant difference to the resources required of your client and therefore to the ultimate outcome. As such, we highly recommend this kind of integrated approach as best practice when working with people with M.E. and their employment goals.

Case example: close liaison between clinician and work coach

"I was off work for a year. Six months in, there was muttering from work about whether I would be able to go back. My employer wanted a return to work date but I was terrified that I would go backwards and have my contract terminated on the grounds of ill health.

"It has made all the difference having someone who looks after me from the clinical side and the employment side. It was absolutely necessary that [SEE M.E.] were in contact with my clinical support, that they were communicating between each other. I had letters of support and everyone was agreeing with one another and there was a shared approach. Every party had all of the information without me having to sort it all. It has made things a damn sight easier."

This client successfully completed an extended, phased return-to-work supported by the combined close liaison of their specialist clinician and employment adviser.

Interventions

- When you first assess a person with M.E. or become aware that they have M.E. and employment-related needs, determine what other forms of support they have in place which may fall outside your own remit.
- Help your client to identify any unmet needs and how/where they can gain support to meet them.
- Non-healthcare professionals will of course be extremely careful not to propose a possible diagnosis to a client. But you can provide useful information for a person to consider and recommend they discuss their health with their GP. Is there a local NHS specialist M.E. service or community peer support group which you could signpost to? Check Action for M.E.'s services directory at www.actionforme.org.uk/find-local-services
- The Disability Employment Advisor (in some areas now called Health and Disability Work Coach) at Jobcentre Plus can provide information, advice and referral to local specialist support.
- If you are signposting or referring your client to another service or are aware that they are attending one, provide them with a brief letter of introduction and/or service leaflet so they can liaise with you as necessary.
- As a work coach working with a client who has M.E. it can be hugely helpful to your understanding and effectiveness of support to speak with their specialist M.E. clinician to gain a good understanding of their condition and the treatment and management plans in place.
- Many people with M.E. find themselves having to consider not working for the first time in their lives and financial concerns may be pressuring them to remain in work at all costs. Ensure you support your client to access financial planning and welfare benefits advice sooner rather than later, to enable informed decision making and help relieve financially pressured decisions.
- Specialist M.E. clinicians should be aware that people with M.E. who are in receipt of ill-health/disability related benefits are not risking a sudden change in their benefit status by engaging with the Jobcentre and there will not automatically be an expectation on them to start job hunting.
- Specialist M.E. clinicians will not usually have time to communicate directly with employers to help advocate on behalf of patients, beyond sending reports on progress and prognosis. If your client is employed but off sick long-term then find out when such letters might be needed, so you can ensure they are available at key review and decision-making points.
- Find out if your patient belongs to a union and send a copy of the letter to the union representative, inviting them to contact you if they would like to talk it through. This way they can clarify their understanding and act more effectively as your client's advocate.

Resources

- See our *Individual needs assessment* worksheet (p 34) which includes sections relating specifically to integration of support.
- See *Sources of information and advice* (p 36) for organisations and services to signpost to and/or coordinate support.

Enabling interventions

Planning for M.E.-appropriate work

Many people with M.E. who find themselves unable to work for a significant period of time wonder what kind of work they may be able to do that is “M.E.-appropriate.”

SEE M.E. received many requests from clients and professionals for a list of such jobs but, as with other long-term health conditions, this list does not exist.

We found it more helpful to support clients to focus away from job titles and instead to explore their skills and interests and reflect on their capacity for work at the time. It was also useful to explore what they may need from an employer and the workplace to enable them to reliably sustain work.

Much of the planning process starts before a person feels ready to work. During the early stages of symptom-management or recovery and rehabilitation it may be that most of your client’s energy is taken up with learning their baseline and how to manage symptoms.

There will be a need for your client to process and adapt as a result of having M.E. Without this, they are unlikely to be able to reliably sustain any work longer term. An awareness of this reality can lead to anxiety and a period of adjusting can help them determine how they could achieve a better balance between what they give to and get from work.

Accessing specialist clinical intervention can enable a person with M.E. to learn the strategies they need to manage their condition and gives an opportunity to learn how they can be integrated into future work plans. Through SEE M.E. we worked with clients who struggled to connect the need to pace day-to-day life with the need to pace themselves within the workplace. Bridging the support between the employment and clinical services can help this process.

Case example: adjusting expectations and building back up

Mary had experienced symptoms of M.E. for many years and had not worked for more than 12 months. She was supported by SEE M.E. to explore her perceptions around returning to work, the kinds of work and use of skills that she found satisfying, and how she could manage disclosing M.E. to an employer.

Mary began volunteering and with the help of prepared notes was able to negotiate a manageable number of hours.

“The first part of the journey to where I am now was a process of readjusting my expectations and coming to terms with being unwell. The holistic approach taken by the specialist M.E. clinic I attended helped me by looking not only at how to improve my physical health but also encouraging me to consider new goals and a new way forward, including thinking about work.”

“I had missed working very much and it made such a difference to have support from a team who understood the kind of barriers I might be facing in terms of returning to work. We were able to work together on coming up with some positive solutions.”

“Volunteering helped me to get out and about when I felt that I had lost a lot of confidence, and to get a sense of how much I could do and what I would really like to do. I retrained in web development and editing so that I had practical skills I could use to work from home as a freelancer.”

“I think what I found most helpful was the practically applicable nature of the advice in regards to how managing the condition fitted into real-life situations. I have felt much more able to broach the subject of my illness which has, in itself, relieved large amounts of the anxiety associated with it. While I believe I was reaching a point of acceptance in regards to my relationship with the condition I believe that attending the course and the advice I received during the sessions was the necessary spark I needed to overcome that hurdle and as a result has helped me move on with my life.”

A month after starting the volunteer role, Mary and her manager agreed that she was ready to increase her hours and take on another shift.

Key principles for planning future employment

Experience gained through SEE M.E. delivery helped to identify the following key principles.

- Progress needs to be slow and steady, building up from a reliable and sustainable baseline.
- It is important to build capacity at an individually appropriate rate and consolidate before increasing (not least because of the need to also adjust to resultant changes to life outside of work and the strategies needed to manage this).
- Perceived barriers to work should be addressed with exploration of potential concrete solutions, to help increase understanding and confidence.

Individual experiences of M.E. are different but common themes emerged through SEE M.E. which impacted on clients' capacity to progress towards their employment goal. These include:

- the need to understand what their "new normal" (see p 20) is and to adjust expectations accordingly, eg. recognising they can no longer work full-time or take on extra responsibilities within their role
- fear about the impact of future work on symptoms and finances, eg. wondering how they will manage on part-time income
- fear that, due to the fluctuating nature of M.E. and the stigma that sometimes comes with it, they will be perceived as lazy and unreliable by employers, welfare benefits assessors and others.

Interventions

- Help your client with M.E. reflect on their skills and what they want/need out of future work.
- Increase understanding and confidence about what they can do by helping them to access volunteering and/or courses. These can be short or online and not directly related to their employment goal. This provides evidence of their reliability to employers and themselves and also be an opportunity to try out ways of working that support their condition management.
- It can help build capacity and confidence to start by agreeing small activities or splitting larger activities into stages.
- Encourage the person with M.E. to think of any work-related activity as part of building up their baseline and encourage them to work with their clinician to do so appropriately.
- Explore the possibility of starting with part-time hours to build their baseline and confidence. Supporting your client to check their eligibility for Working Tax Credits or Permitted Work can help them make best use of their energy.

Resources

The following agencies offer tools that can help explore skills, interests, volunteering and specific job requirements.

- National Careers Service offers free interviews with a qualified careers adviser, plus lists of training and skills courses. Tel: 0800 100 900. www.nationalcareersservice.direct.gov.uk
- I Could is a charity providing career inspiration and information for young people. www.icould.com
- Careers Box is a free online library of careers related film, news and information. www.careersbox.co.uk
- Volunteering information and support can often be found via a local volunteer centre. Lists of centres and adverts for opportunities can be found at www.do-it.org.uk
- Future Learn offers a diverse selection of courses from leading universities and cultural institutions from around the world. www.futurelearn.com
- Alison offers free, certified learning courses. www.alison.com

The solution-focused approach

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

It can be extremely helpful for your client to take an active, positive approach to working out what they need and to communicating this to their employer, whether they are new to the job or have worked with them for many years. Explain to your client that this will give their employer more confidence that they can manage them and their symptoms well and express what they need in order to become or remain a reliable employee.

Challenges, needs and solutions

This is a staged, solution-focused approach that your client can use to reflect on their M.E. symptoms, how they affect them at work, and what may help to overcome difficulties they might be experiencing. Using the headings shown on the worksheet (see 'Resources' below) can help your client organise their thoughts and give them a tool to use when discussing this with their employer.

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

Challenges	Needs	Solutions
List the ways in which the symptoms you experience interact with any aspect of your working life.	List what you really need in order to overcome each challenge. Do not list specific solutions to meet the need.	List the ideas or proposals you have for specific solutions which will help to meet your needs.

For example:

- | | | |
|---|---|--|
| <ul style="list-style-type: none"> • Commuting in rush hour is exhausting and steals so much energy from my working day. | <ul style="list-style-type: none"> • I need to better manage how I spend my energy throughout each working day. | <ul style="list-style-type: none"> • Changing my working hours to avoid rush hour and/or doing some home working. |
| <ul style="list-style-type: none"> • I become fatigued and pained much more quickly from sitting or standing for long periods. | <ul style="list-style-type: none"> • I need to reduce time spent on more fatiguing activities or how fatiguing a particular activity is. | <ul style="list-style-type: none"> • Reviewing my duties and how I carry them out. Perhaps getting a specialised, more supportive chair. |
| <ul style="list-style-type: none"> • I find keeping up with fast conversations in team meetings difficult due to experiencing brain fog. | <ul style="list-style-type: none"> • I need to ensure I can keep up, contribute and take clear notes away from team meetings. | <ul style="list-style-type: none"> • Can we discuss this at the next team meeting as some small changes may help me and be useful for others too? |

Resources

- There is a *Challenges, needs and solutions* worksheet on p 38.

Disclosing M.E. to an employer

Considering whether or not to disclose M.E. to an employer can feel like a difficult decision. Your client may feel unclear about what the law dictates they must do, what exactly to say and to who, and how to handle what happens next.

This can feel daunting and the perceived negative consequences of being open (discrimination and stigma) or not (lack of understanding and support) may be distressing.

Telling an employer

There is no absolute right or wrong when it comes to disclosing M.E. to an employer and there is no legislation that says that a person must do so.

Not telling an employer about a diagnosis of M.E. when asked, which later impacts on a person's ability to work (eg. causes sickness absence), could in a worst case scenario be considered a breach of their contract of employment (due to falsifying or withholding information). This could lead to disciplinary action, including dismissal. However, this is rare, and will depend to a great extent on an employee's relationship with their employer.

Each situation and decision about disclosure will be unique and can be informed by a number of factors. Support your client with M.E. to consider how the following impact upon their decision:

- their current level of symptoms and functioning
- their ability to manage their symptoms and so minimise risk of absence from work
- the specific challenges of the job or working environment – if it is a new job then this might not be very well understood yet; if it is an existing job then there may be concerns or issues that have resulted from reduced performance
- whether they are currently struggling to the extent that it's causing additional distress.

Supporting a person to make decisions about disclosure should focus on empowering them to explore and make informed choices about:

- the benefits of doing so
- the reality of their worries about doing so
- who, when and how to actually disclose, so as to maximise the benefits and minimise risks.

Who to tell and what to tell them

When a person with M.E. has reached a decision that disclosure would, on balance, be a good way forwards, they may be concerned by questions of timing and who exactly they are going to tell.

Key considerations to discuss with your client include the specific current circumstances. For example, are/have they:

- applying for a job in writing or going for an interview
- just been offered a job and are waiting for references to go through
- starting to struggle in a new job and having a progress reviewing meeting with their manager
- been off sick from work for a short period due to symptoms of M.E., which they have had for a long time but have never discussed with their employer
- newly diagnosed with M.E. after a period of symptoms but no certain diagnosis
- off sick from work longer term and their employer is aware of their M.E. diagnosis?

This will provide important information about the legal and employer policy considerations and give some insight into the expectations the employer may have at this stage. For example, will they be likely to refer your client to an occupational health provider for an assessment of fitness for work?

Your client may feel concerned about being suddenly forced into disclosing when they are not ready to do so by a person they do not feel comfortable telling. To help with this concern, ask them to consider:

- their fall-back position on disclosing; in other words, what is right for them rather than right for the person asking?
- what they could realistically and comfortably say which will help them to retain some control over the situation if they find themselves being asked unexpectedly or at an inappropriate time. Could they practice saying this with you or anyone else?

An example of a useful fall-back position statement is: "I am happy to discuss this in a way that is helpful way for us both, but would prefer to arrange a time and place so that we can both be prepared and feel comfortable."

How to tell them

Your client with M.E. may be worried about using the right words, and staying calm, or whether the response might not be very supportive or understanding. Exploring the following can help them to plan how they can go about disclosing. Could they:

- keep it short in the first instance so they don't overwhelm themselves or the person they are speaking with, letting them ask more questions later on
- bring more information with them to hand over, such as Action for M.E.'s *An employer's guide to M.E.* (see p 36)
- write a brief disclosure statement, and hand it over in advance of a meeting or at the start of it
- arrange to bring someone with them to the meeting?

What is your client's relationship with their manager like? Are they likely to be understanding or are they expected not to respond well? If there are concerns based on evidence or experience then what could be done to help with the conversation?

What information should your client share?

The last concern that we will cover here is exactly what kind of information to give to an employer. A really good place to start is the ability to clearly demonstrate an understanding of M.E. and its impact on your client, along with a desire to work together to positively explore effective workplace solutions. You can help by supporting your client to be prepared to talk about:

- the reality of their current situation in terms of M.E. symptoms and the coping mechanisms they use to manage this
- what they are doing to improve and manage their symptoms in order to be fit for work
- what they believe can help them overcome any difficulties they are experiencing at work or in getting there – see the solution-focused approach on p 12
- what further expertise or services are they aware of that can provide further support to them or their employer, eg. their specialist M.E. clinician, Access to Work, work coach. If needs be, could any of these be accessed in order to help prepare for or support the disclosure itself?

"After two and half months off work I am now achieving a greater level of understanding of my illness and symptoms and how this impacts on my daily life. SEE M.E. helped me to more fully understand what I was experiencing and that to some extent I had been misrepresenting my condition to both myself and my employer. Achieving a fuller acceptance of my condition has helped me to move forwards more positively with recovery. I expect now that, when I go back to work, I will take a much clearer idea of how to sustain it more reliably."
SEE M.E. client

Flexible working and contractual variations

There are a number of changes that should be considered for people with M.E. as well as reasonable adjustments and permanent contractual changes. There may be barriers to some types of change being considered or implemented, so here we provide some clarity and advice on how you can help to address these.

The right to request flexible working

Since 2014, after 26 weeks of continuous employment for an employer, an employee has the right to submit a "flexible working request" which can relate to any aspect of when and where work is done. This can include:

- changes to normal working hours or shift patterns
- working from home if possible
- taking longer or more frequent breaks away from their desk/workstation
- attending medical appointments during working hours if required.

Guidance from the Advisory, Conciliation and Arbitration Service (see p 36) on flexible working requests suggests that employees should:

- state what change to working conditions is being sought and how they think this may affect the business, eg. improved performance/cost saving
- state if the request is being made as a reasonable adjustment (it does not have to be)

Employers must have a sound business reason for rejecting any request. Employees can only make one request in any 12 month period.

Interventions

You can support your client with M.E. to:

- build a strong business case to put to their employer, to back up any formal requests for change
- consider whether it would help their request if they made it as a reasonable adjustment – often, employers are concerned about setting precedents which they couldn't uphold if many other employees made similar requests; by submitting the request as a reasonable adjustment this means the employer is making a unique case in direct response to the needs of their disabled employee
- review their employer's response to the request and prepare an appeal if they feel they have not given a sound business reason or failed to fully take the business case presented into account
- consider carefully, before submitting the request, what changes may be needed in the short, medium and longer term over the 12-month period that it will have to cover.

Many people with M.E. have worked full-time all their working life and they and their employers can be entrenched in seeing their job as an all or nothing thing. When a person is unable to work due to M.E. this can sometimes lead to the only contractual option under consideration being termination. The following are other important forms of contract variation that should be considered.

Redeployment

Changing to a different role with the same employer could be considered a reasonable adjustment that might enable the employer to retain a person with M.E. Employers are sometimes reluctant to do this for a number of reasons, including where it may cause a reduction in salary for the employee. So your client may have to assert their desire to explore this in order to be able to remain in work.

A risk with redeployment exists where an employer applies an existing one-size-fits-all policy, such as might be used when an employee is at risk of redundancy. For example, this may mean that they apply a limited timescale over which a suitable alternative role is sought. However, such policies can be "reasonably adjusted" for the specific case, in order to make them appropriate and helpful.

Temporary reduction of hours

Agreeing a temporary reduction in hours might initially be perceived as reducing an employee's income and leaving the employer without cover for a role, but could also be viewed positively and be just what is needed to retain an experienced employee in the longer term.

Your client should be supported to access advice at the earliest possible point regarding their eligibility for in-work benefits to support their income during such a period. This will enable more informed decision-making.

Temporary reduction of hours could be agreed in order to extend a phased return period, eg. agreeing a reduced number of hours for three months so that hours of work throughout the phased return period can be increased only up to this level. See return-to-work planning on p 22.

There could be a longer term temporary reduction in hours, eg. if your client's employer agreed to a 12-month reduction from five to three days of work per week, they could recruit a job-share partner for two days per week for the year. For the employer this brings the benefits of:

- retaining the experienced employee
- possibly giving a development opportunity to another existing employee
- an opportunity to bring in a new employee – this could potentially provide an opportunity to offer an apprenticeship or traineeship position.

Career break or unpaid leave

Some employers have a policy that allows employees to submit an application for a period of unpaid leave. This may be referred to as a career break and may require the employee to have a minimum number of years of service before they can apply. An agreed period away from work can give an employee with M.E. a chance to focus on learning, adjusting and/or recovering, whilst the employer fills their position on a temporary basis. This gives the employer an opportunity to retain the employee in the longer term.

Interventions

- Support your client and their employer to consider how different forms of contractual variation could be used to help meet everyone's needs. Try to encourage a positive approach to this by all parties, as an exploration of possibilities intended to help retain the employee.
- Explore with the employer how reasonable adjustments to policies and procedures can be made in order to make contract variation options appropriate for the person with M.E.
- Example one: Could the standard 12-week redeployment period be extended appropriately in order to give redeployment a realistic chance of success?
- Example two: If a career break policy exists but is not normally intended for use by staff who are struggling with attendance at work due to sickness, then could this policy be adjusted in order to allow it to be used in this way in this specific case for a disabled employee?

Case example: meeting employer and employee needs with a career break

"I realised that all of my energy was going into trying to keep my job and keep my family together and this meant that I wasn't helping myself to recover or manage my condition better. So, with the help of SEE M.E. I put in a request to my employer for a 12-month unpaid career break. In response, 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. Whilst I do have some worries about how I will find the next year, I am relieved that my job is secure while I focus on my health and wellbeing."

Reasonable adjustments

A key approach to coping with M.E. is the management of personal energy expenditure throughout the day, week and month. An understanding of this should therefore underpin the identification of workplace adjustments, eg. enabling an employee to avoid rush hour commuting and park closer to the workplace so they spend less energy getting to work, leaving them with more to fulfil their duties.

The same principle applies to other symptoms, such as pain, brain fog or noise/light sensitivity which your client with M.E. may experience. For example, sensitivity to noise can make it more difficult to concentrate in a loud workplace. Needing to concentrate harder increases energy expenditure and feelings of fatigue. This can, in turn, increase sensitivity to noise. So making changes that reduce a person's experience of workplace noise (eg. where they work, when they work, how much noise is created, using noise cancelling headphones) can be a very effective adjustment.

What can be adjusted and what is reasonable?

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 legal considerations on p 28). 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 them 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.

Interventions

- Ensure that your client is aware that reasonable adjustments could apply to any or all of these and consider, as far as possible, ahead of time what they might request which would enable them to overcome any perceived disadvantages due to their M.E.
- Similarly, in your communication with your client's employer, ensure that they are aware that reasonable adjustments can apply to any provision, criteria or practice applied by them.
- If an employer is going to lawfully deny a specific request, it is their responsibility to set out a clear business case why an adjustment is not reasonable. However, you can support your client to pre-empt this by considering the costs and wider impacts associated with their request and present any proposals for how disruption and cost can be minimised, and the adjustment be most readily implemented into existing ways of working.
- If an employer says no to a specific reasonable adjustment request, support your client to request clarity on why this is and to understand their employer's reasoning. See below for more on addressing employer concerns.

What makes adjustments effective?

The key to determining effective reasonable adjustments is to ensure they are targeted in response to your client's experience of M.E. and to look in close detail at exactly how specific symptoms are being experienced when tasks are being undertaken.

It can be valuable to break tasks down into individual actions where a person is experiencing specific M.E.-related challenges.

Your client and their employer may need your professional assistance to give this initial exploration the full time it needs, especially if your client has only been recently diagnosed (and has yet to develop their knowledge and understanding) or if absence or performance issues at work have reached a level at which the employer is taking disciplinary or capability action.

Interventions

- Review the approach the employer has taken to identifying and implementing reasonable adjustments. Have they gathered enough specific information to enable them to make truly targeted adjustments or are they applying generic adjustments and hoping that they will work?
- Encourage your client and their employer to carefully explore specifically how their symptoms present when they are working (or getting to work) and what they need as a result (see a solution-focused approach on p 12). This may require the employer to put a hold on other procedures while this work is undertaken.
- Assist your client and their employer to gather expertise in a timely manner from sources such as a specialist clinician, occupational health, the Fit for Work service or Access to Work.
- Are any other people, such as a close colleague who knows your client well and their job well, who could help this process?

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 students' 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."*

Reviewing adjustments

It is vital to carry out reviews to check that changes made are helping your client as anticipated. We found that the most effective adjustments are often found after a period of trial and error. For example, if there has been a change in working hours or days it may take several attempts to find what works best.

It can be valuable to record any adjustments that are made with a clear explanation of what the adjustment is, how it is anticipated to help and when it was agreed. As M.E. is a fluctuating long-term health condition, your client's symptoms and needs will vary over time. Planned, regular reviews are a way to objectively capture this and ensure that changes to adjustments are expected and not seen as a problem. We recommend that reviews include:

- an evaluation of the extent to which agreed adjustments were implemented and maintained
- assessment of how effective adjustments have been at overcoming challenges and barriers
- discussion as to what extent current workload and hours are sustainable
- identification of alternative or additional adjustments which may help
- any additional expert input (eg. up to date clinical report or Access to Work assessment)
- agreement of an ongoing timetable for review.

Clear communication

It is important that your client's colleagues are understanding and supportive of adjustments made, rather than unsure or resentful. Clear communication about changes will be needed in some cases. While it is the manager's responsibility to ensure that communication is handled appropriately with the team, given the requirement to keep personal medical information confidential they may need a degree of permission from their employee to be sufficiently open.

Encourage your client and their employer to discuss and clearly agree exactly how any agreed changes are to be communicated to colleagues. We also recommend that written records of adjustments are made to ensure that they can be clearly reviewed on a regular basis and when line management or operational changes occur.

Addressing employer concerns

Employers sometimes wish to manage employees' expectations around what can realistically be adjusted and as a result may not be entirely open to a full exploration of possibilities. In our experience, a lack of openness can be inferred by clients as a lack of desire to provide individualised support. This is more likely to lead to a grievance or legal action against an employer for a failure to make reasonable adjustments.

Cost can be the main reason why employers often manage employees' expectations around what changes can be put into place, or say no to specific requests.

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?"

Interventions

- Support your client and their employer to fully explore everything that might help, sooner rather than later, with a shared understanding that not every possible adjustment will be practicable. Consider writing to your client's employer to encourage this approach and offer your assistance.
- Support your client and their employer to explore other sources of financial assistance to make adjustments, eg. Access to Work, which in our experience most employers are not aware of. You can provide your client with information on Access to Work and/or write to inform the employer and offer to liaise with them to support your client/their employee's application.
- Support your client's employer to understand that, as adjustments are targeted for your client's unique situation, they do not automatically become applicable to anyone else. Recommend they document all adjustments in a way which demonstrates that they are specific responses to an individual's needs and include any clinical guidance which underpins the agreed changes.

Access to Work

Access to Work is a government programme which provides financial support to help enable disabled people and people with long term health conditions to overcome disability-related barriers to work.

It is not a benefit to which disabled people are automatically entitled to, but can be applied for when a person with M.E.:

- currently has a job
- has just been offered a job (and is disclosing their M.E. and discussing what they may need)
- is self-employed or running a small business (paying themselves at least national minimum wage).

Through a process of advice and assessment it 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 and from work or in work
- support workers
- training and coaching.

Access to Work will only fund 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 (see p 17) and may recommend support or equipment which it part-funds and expects the employer to also contribute to.

The objective of Access to Work-funded equipment and support can be seen as aiming 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.

Through the SEE M.E. project we found that:

- support and equipment funded by Access to Work made a crucial difference to people with M.E., enabling them to secure new jobs, work more and retain employment
- far too few people know about or recommend Access to Work to people with M.E., including employers, occupational health specialists, clinicians and employment advisers
- people are much less likely to apply for Access to Work when they are unable to identify exactly what Access to Work may actually fund.

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.

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.

Interventions

- Tell your client with M.E. about Access to Work at the earliest possible opportunity and support them to fully explore what it might mean for them. This can help to bridge gaps in their perception of what and how much work they could realistically do.
- Support your client to make and follow up on their application, as it may be a task too much for them right now, even though it might make a huge difference to them in the longer term.
- Support your client to prepare for their workplace assessment by thinking through the challenges or barriers they experience and what they need to overcome these (the challenges, needs and solutions worksheet on p 38 may be helpful with this).
- Make yourself available to liaise with the Access to Work advisor (or workplace assessor) to provide additional information or tackle any problems which may arise during the process, as they may not have your level of understanding of M.E. and associated barriers at work.

Resources

- For further information about eligibility, how to apply and what to expect from Access to Work, visit www.gov.uk/access-to-work
- Disability Rights UK provide an excellent, independent factsheet on Access to Work. www.disabilityrightsuk.org/access-work

Return-to-work planning

When a person is signed off sick from their current job it can sometimes be hard to imagine how returning to work could happen. Many people will follow their employers lead and do not feel that they can be pro-active in suggesting solutions, or that they may disagree with employers suggested plans as they feel unrealistic and unachievable.

Planning to return to work should be a process of negotiating a well-informed plan, based upon what 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 client with M.E. to start planning their return to work, it can be difficult to gauge the right timing – too early and it can feel overwhelming, but leaving it too long can create anxieties for your client and their employer.

We found that starting the planning process early on helped maintain a positive dialogue between our clients and their employers, provided a longer term, realistic view of the process was maintained. Concrete solutions help to bridge the path back to work and build confidence that it will be successful and sustainable. It is also important to remind your client and their employer that the plans are a starting point to be reviewed regularly and adjusted if needed.

Fitness for work is not an all-or-nothing thing and 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 your client 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 all of the following, most of which are covered in detail in other sections of this toolkit:

- accessing clinical advice (see p 24)
- a phased return-to-work period (see below)
- flexible working arrangements (see p 15)
- reasonable adjustments (see p 17)
- Access to Work (see p 20)
- how it will be reviewed and sustained in the longer term (see p 19)
- confidentiality and communicating with colleagues (see p 23-24).

An M.E.-appropriate phased return to work

A phased return to work is a commonly used approach to supporting employees who have been off sick from work. It is a period over which working hours are built up towards the fully contracted number, while in receipt of their full salary.

Many employers have a policy which states a maximum 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 and sustainable.

In addition to a formal phased-return period, a longer staged return to work could also include:

- use of annual leave (to shorten days as well as the working week)
- a reasonable adjustment to the phased return policy which recognises that an effective and appropriate specific adjustment for your client with M.E. is likely to be a longer, slower period over which to increase hours
- a temporary variation in the contract to reduce the hours that are being increased towards (and therefore also salary for the period).

A return-to-work plan provides a clear supportive framework to the phased return. It is important to help the employer understand that your client with M.E. is trying to plan for success gradually, rather than take risks, and it is success in the longer term that should be more important.

Within a phased return period, an employer should consider:

- building up work or work-related skills at home at first
- planning in some home-working days once they have started to return to the workplace (to reduce the amount of energy spent on commuting)
- building up their workload or targets and hours to increase confidence about what is manageable. Very often 50% workload or targets to be achieved in 50% of the time is going to be relatively harder, potentially stressful and unlikely to build up anyone's confidence
- allowing for regular breaks and perhaps a longer lunch to build in rest periods which are in an appropriate place.

It is important to plan in flexibility to such plans to make allowances for setbacks or relapses, which might be expected. It can be helpful to reassure your client with M.E. that they can expect to find it challenging at times and that some of their symptoms may feel worse to some extent, for some of the time. Clinical input and their own experience can help assess whether this is a sign to stop or whether it is tolerable and may get easier over time.

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. were 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."

Confidentiality

It is advisable to ensure that the key points discussed and agreed with an employer are recorded in writing, so that they can be referred back to later. If cognitive difficulties are a problem for your client with M.E. they can ask in advance for a written summary to be taken and provided afterwards. It is especially important to have a written record of any changes which impact upon their job role, salary or other terms and conditions of employment.

If no written record is taken in a meeting (eg. because your client had an unplanned, informal conversation with their manager), then we suggest they write their own summary and seek confirmation that they have understood fully and that your notes are accurate. This provides a formal, written record of what has been agreed as managers and others involved may change.

The employer should keep personal matters discussed as confidential, within both company policy and agreements made with the individual. 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 client and their M.E. should not be shared with any other person, inside or outside the organisation, without their prior, expressed consent. Your client's manager may need to raise certain matters with their own line manager or human resources department to seek further advice or guidance. You will also need explicit consent (according to your organisation's data-sharing procedures) if you are going to talk to an employer on behalf of your client with M.E.

Communication with colleagues

Maintaining good communication with colleagues is important in terms of professionalism and good will. A phased return to work may mean changes for other colleagues or at worst could cause resentment among others unless they understand why it is happening. Encourage the person with M.E. to discuss with their manager what needs to be communicated to whom and when.

Interventions

- Start to explore return-to-work planning sooner rather than later, even if it is a case of introducing the subject to be followed up at a later meeting.
- Consider with your client how clinical expertise can be requested and incorporated.
- Explore with all parties what a phased return could look like beyond the standard as defined by the organisations policies and procedures.
- Reassure your client that a phased return and return-to-work plan is a way of formalising a gradual return to the workplace that supports their condition management, rather than forcing them into returning to work too soon.
- Encourage a pro-active, solution-focused approach that helps an employer understand how they can help most effectively.
- Support your client and their employer to fully and separately consider how stages of a phased return-to-work plan, flexible working arrangements, reasonable adjustments and Access to Work might contribute to an effective plan.
- Work with your client, their employer and other experts (eg. clinicians, union representatives) to draft, negotiate and review the return-to-work plan until all parties feel that it is appropriate.
- Recommend that your client's employer build in reviews which celebrate achievements and support positive changes where needed, rather than look for failures and problems.
- Support your client and their employer to consider how best to communicate to other employees that which is necessary for supporting the plan and any impact upon colleagues.

For clinicians: producing reports and letters

When producing a report for an employer, timing is as important as the content. Your client will need the report to have arrived with their GP (by the time a Fit Note is being issued) or occupational health practitioner (by the time an assessment is being conducted). By doing this you are ensuring that your specialist opinion is provided at the times it can most effectively inform your client's employer, through their own formal decision-making processes.

Record when your client's next Fit Notes and occupational health assessments are due, and diarise a reminder to check in with your client and produce a letter or report for them.

Fitness for work reports

An allied health professional's fitness for work report expands upon the Fit Note and makes use of additional expertise from, for example, occupational therapists and physiotherapists to assess the specific difficulties your client may have at work, and to make recommendations on adjustments and goals for sustainable return to work planning. The report can stand alone or be used as additional evidence to supplement GP Fit Notes and to inform Occupational Health assessment. The report and associated guidance can be accessed through chartered professional societies and federations.

You can effectively support your client's position and the implementation of well-informed reasonable adjustments and return-to-work planning by:

- laying out letters out in clearly titled sections, helping to draw the reader's attention to the key points you are making
- making it as tailored to your client and their work environment as possible
- providing clear guidelines to work with, rather than broad opinion, and offering a clear evidence-base for your recommendations
- avoiding generalisations by referring to other people with M.E. except when it helps to put points in context
- explaining concepts such as post-exertional malaise where this will help to increase the reader's understanding and improve their implementation of adjustments
- providing detail of your client's pacing or graded activity plans where appropriate, along with brief reasoning behind these approaches, in order to increase employer confidence in their efficacy
- taking great care with what you state is a reasonable adjustment – all workers have the right to a safe and healthy working environment and to make flexible working requests (see sections flexible working on p 15 and legal considerations on p 28)
- reflecting on the efficacy of a specific requested adjustment with reference to your experience and applicability to the specific situation
- copying additional people (eg. union representative) in to the letter with your patient's consent
- recommending other sources of expertise such as Action for M.E. and Access to Work.

In the absence of a clear prognosis for recovery, many employers are left with a poor view of an employee's ability to return to work. Be as clear as you can be about what you perceive is the positive pathway forwards for your client in line with their symptoms and abilities. Even if you cannot put your finger on exactly how much they might improve and over what timescale, you can state your expectations.

Sustaining work

Ultimately it is not walking in the door on day one which causes most anxiety about returning to work, but sustaining that work. Throughout this toolkit we have addressed many key approaches to sustaining work in the longer term and here will focus on additional factors and actions which can have a positive or negative impact on this.

Expecting changes

The nature of M.E. as a fluctuating, long term health condition means that there are likely to be changes in nature and severity of symptoms, which adds an additional challenge to sustaining work.

Often during the SEE M.E. project we found that, after clients had put in place reasonable adjustments and settled into their new routine, factors would come into play that had potential to derail the success of the process. These included temporary workload increases, demands from home life, a change of manager and operational changes.

“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

In the longer term an additional factor can be that all parties become more comfortable and forget the need to maintain helpful strategies. Additionally your client 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.

Planning for fluctuations

It will be helpful to make plans that take such factors into account through scheduled regular review, rather than as a response when problems have occurred. This should be a cycle which, we recommend, is incorporated into regular employee meetings and reviews and approached in a pro-active and supportive manner.

“The practical strategies to help manage the cognitive symptoms of M.E. at work were particularly useful – I keep a list of these with me at work as a reminder – as was the advice and encouragement I received about communicating my needs to my employer.” SEE M.E. client

This approach is more sustainable, less time consuming and less costly for employers than reviews triggered by absence or poor performance. Helping your client to reflect on how they are combining their clinically informed condition-management strategies with their employer’s workplace approaches will support them to sustain work and manage their symptoms.

Interventions

- Support your client to review any reasonable adjustments in place which have or could be liable to slipping. Consider why this is and what is needed to support their ongoing use.
- Reflect with your client on how effectively they are maintaining their day-to-day condition management strategies, even when they are feeling well, in and out of work. Are they taking any breaks that have been recommended? Are they managing their work within their contracted hours? If not, encourage them to discuss this with their employer as part of a review process.
- Consider recommending a workplace mentor who could support the maintenance of adjustments and contribute to reviews. It can be helpful to have someone impartial as a sounding board to explore how they feel they are managing and reflect back where they see strategies slipping.
- Work with your client and their clinician to review their condition-management strategies and address reasons why they might not be being put into practice.
- Work with your client's employer to identify periods of likely increase in workload. What strategies can they put in place to mitigate this?
- Ensure that an appropriate balance between work, rest and play is maintained over the longer term.



Legal considerations

This section provides clarity around key legal issues which can have a bearing for people with M.E. It is not intended as definitive interpretation of the law and sources of legal advice can be found on p 36-37.

The Equality Act 2010 and M.E.

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.

What does the Act do?

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 M.E., whereas 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 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.

- for an employer to subject an employee to a detriment (eg. dismissing, treating them unfairly or disciplining them) because they have carried out a 'protected act'. This is known as victimisation. A 'protected act' can include making an allegation that they have been discriminated against because they have M.E.; requesting a reasonable adjustment; or previously bringing a legal claim of disability discrimination against your employer.
- except in certain special circumstances, for employers to ask about a job candidate's health before offering them employment. In most cases this can only be asked after a conditional job offer has been made.

It is worth bearing in mind that an employer must usually know that an employee is disabled before that employee can bring a claim of disability discrimination against their employer. The employer usually knows that their employee is disabled because:

- their employee has told the employer that they have a long term condition that has a substantial impact on their ability to carry out day-to-day activities.
- they have obtained a report from Occupational Health or another medical practitioner which advises that the employee is disabled.

What does this really mean?

Many employers are aware they have a duty under the Act but may not know how it applies to a person with M.E. In many cases employers seek expert advice on their employee's rights and what reasonable adjustments might be applicable, such as by referring to occupational health.

However, it sometimes results in an employer not treating the person with M.E. as a 'disabled person' and not making reasonable adjustments. In some SEE M.E. cases we experienced employers implementing basic adjustments, which they feel are reasonable (in that they do not have too much of an impact upon operations), but which don't effectively address the disadvantage the person with M.E. is experiencing. In our view this does not fully meet their obligations under the Act.

It is important to note that:

- employers' duty to make reasonable adjustments is triggered when a provision, criteria or practice or physical feature of the employer or their premises, puts the disabled employee at a disadvantage when compared with a non-disabled employee.
- tribunal court cases have clarified that it is the effects and not the underlying causes of the 'disability' which have to be taken into account when considering reasonable adjustments. In other words, employers are required to make reasonable adjustments to remove disadvantages caused by a person's M.E., not to prevent it or avoid exacerbating symptoms. However, this may be where the Health and Safety at Work Act comes in.

The Act cannot actually prevent an employer from treating a person unfavourably in the first place, but it does mean that a person may take legal action if they believe that this has happened. Taking a case to an employment tribunal is not an easy option though and we recommend that people first seek expert advice, such as from Advisory, Conciliation and Arbitration Service (ACAS) to see if the situation can be resolved without legal action.

It is important to bear in mind the time limits for taking action in a discrimination case. An employee will have three months less one day from the date of the discriminatory decision or discriminatory treatment to take legal action. The first step in taking legal action will involve contacting a body called ACAS to start a process called Early Conciliation, a month long period in which the employee tries to negotiate a settlement of their potential claims with their employer. If negotiations are not successful the employee will be issued with a certificate confirming that they went through Early Conciliation and will have at least a month from that date to make a claim to the employment tribunal.

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.

If your client believes that the work environment is impacting upon their health and that some changes could be made to address this, they may be able to raise this as a health and safety at work matter (rather than a reasonable adjustment request). 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. In such cases the changes are likely to benefit other employees, too.

If your client 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 their employer. For example, if a person with M.E. finds their concentration is impaired whilst using potentially dangerous machinery, then clearly this would need to be addressed.

Stress at work

These health and safety at work acts and regulations place a responsibility upon employers to minimise the risk of stress-related illness or injury to employees. This means that 'work-related stress' is viewed seriously in law and that employers are expected to respond appropriately when employees raise issues and concerns relating to feelings of stress, or an exacerbation of M.E. symptoms due to excessive stress.

Many employers will not immediately see the link between stress and M.E. or the specific impact it may be having on your client. A letter or report from the GP, specialist clinician or occupational health professional can help to make this clearer.

Interventions

- Support your client to increase their understanding of their rights under the Equality Act 2010 and the range of health and safety at work acts and regulations.
- Consider how the situation might be resolved without the need for legal action.
- Consider whether your client thinks they may have rights which are not being upheld by the employer and their options for action.
- If needed, signpost them to specialist advice, and help them to interpret any new information as it relates to them. Do consider the additional energy that this will require and how you can best support them to effectively access it (eg. by phone).
- Consider supporting your client by requesting or writing a letter which gives your opinion on their rights as a disabled person. Whilst the employer may have their own view and only a court can determine this for certain, your view may carry some helpful weight and your letter shows the employer that the situation is being independently considered.
- Support your client to consider the most effective way and time to assert their rights in order to achieve their goal. For example, standing one's ground at an early stage, based upon one's rights and offering positive solutions can be more effective than later raising a grievance or taking legal action because of an employers' failure to make reasonable adjustments.

Good practice in providing this support to a person with M.E. includes:

- keeping your focus on what they tell you is their longer term goal and gently guiding them through their own preferred course of action towards this. For example, if their goal is secured and sustainable employment and income then pursuing legal action may help with this, as would moving on and seeking alternate employment.
- attending to whether they are reacting emotionally to how they perceive they have been treated or are they responding with considered, objective action towards their goal.

- assisting them to consider the personal resources that they will need in order to take legal action and the potential impacts. This includes the time and effort involved and the potential impacts of that for them, and the financial cost. There is an "issue fee" (currently £250) to be paid to start a claim to a tribunal court and a "hearing fee" (currently £950) for the claim to be heard in court. There also potential for uncertainty, anxiety and stress: how they will manage these and their impact upon themselves and other people close to them? How they will move forwards positively if they don't win their case?
- considering whether your client is entitled to a fee remission if their capital is less than £3,000 and if they are receiving certain benefits or have a low monthly income.

In-work welfare advice

From case experience gained through the SEE M.E. project and Action for M.E.'s Welfare Advice and Support Service, we know that people with M.E. are often aware of some aspects of welfare benefits regulations and that the professionals working with them often signpost them to local welfare advice.

However, we have learnt that many people with M.E. and those working with them are unaware of the full range of welfare benefits available, especially those to which people who are in employment may be entitled.

For example, it is possible for a person to claim:

- Employment and Support Allowance (ESA) when employed but not/no longer eligible for Statutory Sick Pay
- Working Tax Credit, as an income top-up when salaried earnings are low
- Personal Independence Payment (PIP), which has replaced Disability Living Allowance for people of a working age. PIP is a non-means tested benefit that is designed to help with the extra costs of living with a long-term health condition or disability.

The welfare benefits system is very complex and we recommend signposting your client to a complete benefit check to see what they may be eligible for. This will depend on their age, income and personal circumstances.

Through SEE M.E. we encountered people with M.E. who are working hours beyond a level that was sustainable for them, but felt that they have no choice because they could not financially afford to reduce their hours and income. What most of these clients were unaware of was their potential eligibility for in-work and non-means tested benefits which can help to top-up their salaried income. In some cases a claim for such benefits can make enough of a financial difference to enable them to scale back their working hours to a more manageable and sustainable level.

Interventions

- Support clients to be fully aware of their welfare benefits entitlements as soon as you know they are making decisions which include financial/income considerations.
- Consider together how they can best access welfare advice, bearing in mind the additional resource it may take. Would a telephone service be more accessible for example?
- Support clients to access financial/budgeting support (eg. Money Advice Service) to help them reflect on what is realistically financially viable in relation to their household circumstances.

Resources

- Action for M.E.'s Welfare Advice & Support Service can offer expert information and advice for people with M.E. Tel: 0800 138 6544. www.actionforme.org.uk
- SEAP's benefit support app (www.c-app.org.uk) can help your client prepare to apply for Employment and Support Allowance or Personal Independence Payment by testing any application form answers they have drafted to estimate how many points they might score.

Resource one: Key things to remember

This good-practice summary indicates key things to remember throughout your work with clients who have M.E. Each is expanded on further elsewhere in the toolkit.

Understand M.E.

Myalgic Encephalomyelitis (M.E.) is a chronic, fluctuating, neurological illness that is significantly more disabling than most other chronic health conditions. Its key symptom is post-exertional malaise, the body's inability to recover after expending even small amounts of energy. Additional symptoms can include chronic pain, cognitive difficulties and autonomic dysfunction. Individuals with M.E. can vary enormously in their experience of the illness, and there is no universal presentation in terms of symptoms and their impact.

Work with your client's personal experience

M.E. can restrict a person's ability to pursue their work and career aspirations. Accepting limitations and modifying expectations in relation to employment, as well as other areas of life, can be a particularly challenging part of adjustment. Retaining aspirations that positively affirm your client's identity and role in life can be a crucial factor in what can be achieved and how fulfilling or distressing the experience is. Believe fully in the aspirations of your client with M.E. and support them to identify and pursue achievable goals with a realistic, longer term approach.

Integrate the support you offer

Take the time needed to ensure that you are working collaboratively with other professionals who are supporting your client with M.E. When the person you are supporting has less physical and mental resources available to them, which they may be using to address a greater number of needs, the integration between professionals goes a long way to improving outcomes.

Plan for M.E.-appropriate work

Encourage clients to focus away from the idea of specific M.E.-appropriate jobs and instead to explore their skills and interests, capacity for work and what they may need from an employer and the workplace to enable them to reliably sustain work. Support them to access voluntary work and/or training to help build capacity and confidence, and consider career direction. Support them to explore Access to Work and reasonable adjustments to build a picture of how they might be supported in the workplace.

Advise on disclosure

The Equality Act 2010 makes it unlawful (under most circumstances) for employers to ask about health or disability prior to making a job offer. The reason a person with M.E. may choose to disclose is to benefit from doing so. Support your client to carefully consider when and how they wish to disclose and to focus on identifying potential solutions rather than presenting problems. Provide your client with an introductory letter to give to their employer so they know that you are available to assist.

Take a solution-focused approach

Support your client to identify their challenges, needs and solutions. Challenges are interactions between symptoms and aspects of work which place them at a disadvantage (eg. commuting is exhausting and makes it harder to work). Needs are how the person could overcome the disadvantage (eg. to be less exhausted when starting the day). Solutions are specific ways in which needs can be met (eg. avoiding rush hour or working from home). Solutions require discussion and agreement with the employer and expert input can be brought in from Occupational Health and Access to Work.

Discuss flexible working arrangements and contract variations

Whilst rights as a disabled person and reasonable adjustments are important, many flexible working arrangements or contractual variations are available to all (including non-disabled) employees which can be looked at first and implemented very early on, such as flexible working pattern requests. Could the employee and employer both consider a temporary contract variation, eg. to work part-time (perhaps job-sharing) for 12 months, in order to give them sufficient time and space for learning symptom-management, adapting to changes and achieving a more sustainable level of functioning?

Highlight reasonable adjustments

Effective reasonable adjustments are targeted specifically at the way in which symptoms create challenges that disadvantage your client with M.E. It can take a period of trialling and tweaking adjustments to determine the best fit for the individual, eg. exactly which hours are worked on which days. 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.

Highlight Access to Work

Ensure that your client with M.E. is aware that they can apply to Access to Work and broadly what it could potentially fund. It does not matter if they cannot imagine how it could help them as that is what the independent workplace assessment element will determine. This is just as important for people who are thinking about future work as it is for people who have been offered or already have a job. Support the process by assisting your client to think of what challenges need overcoming and what questions they have about how they might be supported.

Start return-to-work planning as early as possible

Discussions around planning a return to work should be started as early as possible. It is a process of making informed decisions based upon what is believed will be most likely to succeed for an individual rather than being determined solely by a one-size-fits-all policy. A phased return should be gradual as recommended by clinical advice and increase slowly both in terms of hours and complexity of tasks. Plans (including any reasonable adjustments) should be recorded and include planned reviews.

Timetable clinical reports and letters

Ensure clinical reports and letters are in the right hands at the right time so that their content is fully taken into account by employers and occupational health providers. This supports your clinical advice being more readily built into return-to-work and reasonable-adjustment planning. Could you copy in a union representative or other advocate with your client's consent? If your client wishes to retain their job, in the absence of a clear prognosis for recovery, could you give clear reasoning for positive expectations? For example, if your client has only recently been diagnosed and is still learning to manage their activity levels and symptoms, then there is reason to believe that progress can be made.

Consider how work can be sustained

Sustaining work whilst managing M.E. can create challenges because of the fluctuating, long term nature of the condition. Planning for fluctuations with regular reviews of adjustments and open communication between the employer and employee is crucial to minimising the impact of periods of increased symptoms. A workplace mentor can help the individual reflect on how they are managing to maintain their strategies and recognising the need for an appropriate balance between work, rest and play. It also helps to build an atmosphere of understanding and support at work.

Be aware of the legal considerations

Equality and Human Rights Commission guidance lists M.E. and CFS as long term conditions which may qualify someone with M.E. as a disabled person as defined under the Equality Act 2010. There have been tribunal court cases which passed judgements upholding the rights under the Act of people with diagnoses of M.E. The duty on employers to make reasonable adjustments applies to the effects and not the causes of M.E. (eg. work stress). However, health and safety at work regulations can support a person with M.E. to request changes to their work and workplace which are exacerbating their symptoms.

Signpost to in-work welfare advice

Many people with M.E. will have had no interaction with the welfare system and little awareness of the financial support available to them if they were to reduce or stop working hours. Financial pressures can make a person feel that they simply have to keep working, despite the challenges and harm that may result. In-work benefits can top-up salaried income enough to enable a person with M.E. to reduce their working hours. Make sure your clients are supported to fully understand what they may be entitled to so they can make informed decisions.

Resource two: Individual needs assessment

The aim of this assessment is to increase:

- shared understanding of the client's current experience of M.E., condition/symptom management and engagement with healthcare services
- shared understanding of the client's employment situation in relation to their goals and aspirations
- integration of services and effectiveness of support provided.

Understanding your M.E. experience

1. When were you diagnosed, by whom (eg. GP, specialist M.E. clinician) and where was this?
2. Are you accessing any healthcare services in relation to your M.E.? If so, who and how are they currently supporting you?
3. What does this diagnosis mean for you personally?
4. How are you currently managing your M.E.? What symptom and life-management strategies are you using? Are any of these clinically recommended strategies (eg. pacing)?
5. To what extent do you feel your M.E is affecting your work situation? Can you describe specific examples?
6. What symptoms or aspects of your experience of M.E. are most impacting upon you in relation to working or seeking work (eg. pain, brain fog, fatigue)?

Understanding your employment situation

1. What is your current work situation and activity in relation to work? (eg. job seeking, volunteering, working, off sick from work)
2. In what ways are specific M.E. symptoms affecting your ability to pursue your work goals?
3. How much do you know about the services and support available to you?
4. How much do you know about your relevant rights? (eg. as a worker, as a disabled person, health and safety at work)
5. What is happening to support you to overcome any M.E.-specific barriers to work? (eg. return-to-work planning, reasonable adjustments, Access to Work)
6. **If currently employed** Have you disclosed your diagnosis to your employer and how did you manage this?
7. **If currently employed** What sickness absence from work (including current) have you had over the last year?
8. **If currently employed** What has been your employer's response to your absence or disclosure?
9. **If currently employed** Are you aware of your employer's relevant policies? (eg. sickness absence management, equality and diversity)
10. **If currently employed** What procedures are being followed by your employer to support you? (eg. referral to occupational health, return-to-work planning)

Integrating support

1. Who are you currently receiving support from in relation to your M.E. and work goals? (Include names, contact details and brief other relevant information)
 - Health or social care (eg. GP, specialist M.E. clinician)
 - Employment support (Jobcentre Plus, careers adviser)
 - Other professional support (eg. Trades Union)
 - Personal support (eg. partner or colleague)
 - Welfare benefits or financial advice
 - **If currently employed** Employer
 - **If currently employed** Line manager
 - **If currently employed** HR department
 - **If currently employed** Occupational health
 - **If currently employed** Vocational rehabilitation (eg. through company income protection insurance)
 - **If currently employed** Colleagues
 - Other
2. Describe how, if at all, any of the people involved in supporting you are in contact with each other?
3. How could you benefit from specific people involved being in closer contact?

Financial

1. What income are you in receipt of and how secure and sufficient is this?
 - Salary
 - Sick pay (statutory and contractual)
 - Income protection insurance:
 - Pension
 - Welfare benefits
 - Other
2. To what extent is your current or expected income informing your decisions about work?

Goals and support needs

1. What are your employment (and related) goals or aspirations?
 - Short term
 - Longer term
2. What do you want me to help you achieve?
 - Short term
 - Longer term

Actions

(Note where actions are for yourself or for your client)

- Understanding M.E.
- Understanding employment situation
- Integrating support

Resource three: Sources of information and advice

Advisory, Conciliation and Arbitration Service (ACAS)

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

Tel: 0300 123 1100

www.acas.org.uk

Access to Work

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

Tel: 0345 268 8489

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

www.gov.uk/access-to-work

Action for M.E.

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

Tel: 0117 927 9551

Email: admin@actionforme.org.uk

www.actionforme.org.uk

Action for M.E. Welfare Advice & Support Service

For specialist information and advice regarding welfare benefits

Tel: 0800 138 6544 (call for opening times)

Email: welfare@actionforme.org.uk

Citizens Advice

Free, independent, confidential and impartial advice

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

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

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

Northern Ireland: 0289 023 1120. www.citizensadvice.co.uk

Equality Advisory and Support Service

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

Tel: 0808 800 0082

www.equalityadvisoryservice.com

Fit for Work

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

Tel: 0800 032 6235

www.fitforwork.org

Jobcentre Plus

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

Tel: 0345 604 3719

www.gov.uk/contact-jobcentre-plus

Labour Relations Agency (NI)

Information and advice on employment-related disputes in Northern Ireland

Tel: 028 9032 1442

www.lra.org.uk

Law Centre

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

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

Scotland www.scotlawcentres.blogspot.co.uk

Money Advice Service

Free and impartial advice about debt and financial matters

Tel: 0800 138 7777

www.moneyadviceservice.org.uk

National Careers Service

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

Tel: 0800 100 900

www.nationalcareersservice.direct.gov.uk

National Debtline

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

Tel: 0808 808 4000

www.nationaldebtline.org

Office for Disability Issues

Information and advice about the Equality Act and other relevant legislation

Tel: 020 7340 4000

www.gov.uk/government/organisations/office-for-disability-issues

Pensions Advisory Service

Provides free information, advice and guidance on pension schemes

Tel: 0300 123 1047

www.pensionsadvisoryservice.org.uk

Resource four: Challenges, needs and solutions worksheet

Challenges	Needs	Solutions
<p>List the ways in which the symptoms you experience interact with any aspect of your working life.</p>	<p>List what you really need in order to overcome each challenge. Do not list specific solutions to meet the need.</p>	<p>List the ideas or proposals you have for specific solutions which will help to meet your needs.</p>
<p>For example:</p> <ul style="list-style-type: none"> • <i>Commuting in rush hour is exhausting and steals so much energy from my working day.</i> • <i>I become fatigued and pained much more quickly from sitting or standing for long periods.</i> • <i>I find keeping up with fast conversations in team meetings difficult due to experiencing brain fog.</i> 	<ul style="list-style-type: none"> • <i>I need to better manage how I spend my energy throughout each working day.</i> • <i>I need to reduce time spent on more fatiguing activities or how fatiguing a particular activity is.</i> • <i>I need to ensure I can keep up, contribute and take clear notes away from team meetings.</i> 	<ul style="list-style-type: none"> • <i>Changing my working hours to avoid rush hour and/or doing some home working.</i> • <i>Reviewing my duties and how I carry them out. Perhaps getting a specialised, more supportive chair.</i> • <i>Can we discuss this at the next team meeting as some small changes may help me and be useful for others too?</i>



Acknowledgements

This resource is based on the considerable knowledge and experience of Paul Davey, Project Coordinator, and Amanda Mason, Employment Adviser, who delivered our specialist 18-month pilot project, Support, Empower and Employ people with M.E. (SEE M.E.) in 2015-16.

SEE M.E. was funded by the National Lottery through the Big Lottery Fund, the Henry Smith Charity, Lloyds Bank Foundation, Rayne Foundation, Denman Charitable Trust and Dame Violet Wills Trust.

Action for M.E. is also enormously grateful to the following people for their input, expertise and experience:

- everyone who took part in the project, particularly those with M.E.
- our service delivery partner North Bristol NHS Trust and the professionals based at its specialist M.E. service
- Action for M.E. medical advisors Dr Gregor Purdie and Prof Julia Newton
- all those in our Patient and Carer Reference Group who reviewed this toolkit.



LOTTERY FUNDED





42 Temple Street
Keynsham
BS31 1EH

T 0117 927 9551
E admin@actionforme.org.uk
www.actionforme.org.uk



www.facebook.com/actionforme
www.twitter.com/actionforme

Registered charity

Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452
Company limited by guarantee, registered in England no. 2906840
©Action for M.E. September 2016