EMPLOYMENT ISSUES

What you need to know about your employment rights

Including:

- The Law and Disability
- Returning to Employment
- Reasonable Adjustments
- Employment and Sickness
- National Insurance and State Pension
- Ill-health Early Retirement
- Income protection
- Insurance
- Termination of Employment
- Community Comments

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DISCLAIMER

The ME Association is unable to provide personalised benefits advice. However, we aim to provide guidance to the kind of welfare benefits that people with ME/CFS or Long Covid and those who care for them might be entitled. The guidance that we give – and any signposting to external resources – is for information only. We cannot be held responsible if you decide to engage an external service provider who might charge a fee for benefits advice or representation.

EMPLOYMENT ISSUES

CONTENTS

3 Introduction

4 Stay up to date

5 The Law and Disability
- Overview
- The 2010 Equality Act. Section A5

6 Returning to employment
- Overview
- Discussions with an existing employer
- Medical disclosures
- 10 Reasonable adjustments
- The 2010 Equality and Human Rights Act: Codes of Practice
- Practical adjustments
- Benefits and government help
- The Health Adjustment Passport (HAP)

17 Employment and sickness
- Ill-health: the early stages
- Sick Leave and Fit Notes
- Getting a Fit Note
- Self-certification
- Returning to work
- Sick Pay
- Benefits and financial support
- Employment and Support Allowance (ESA)
- Personal Independence Payment (PIP)

32 National Insurance and State Pension

34 Ill-health early retirement

38 Income Protection Insurance (IPI)

40 Termination of Employment

42 Community Comments

46 How we can help

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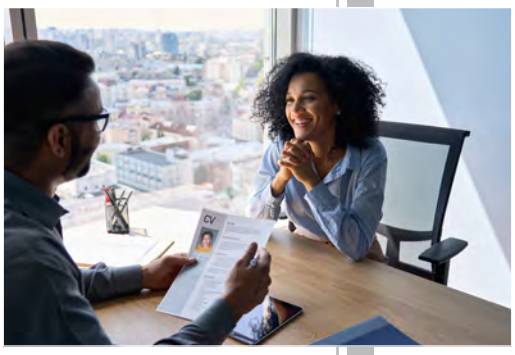
INTRODUCTION

Employment can bring many benefits. For those lucky enough, it can be more than just a job; it can help you feel valued and provide purpose and responsibility. It can be a career and even a vocation. It's where you can make friends. It can assume such importance that it becomes part of your identity.



For most people, employment is a necessary part of adult life whose main purpose is to provide an income that helps pay the bills and provide you and your family with a place to live.

It can stimulate and be satisfying, but employment can also be difficult, stressful, mundane, soul-destroying, and lack direction. For most people, it is a necessary part of adult life whose main purpose is to provide an income that helps pay the bills and provide you and your family with a place to live.

It is not then surprising that having to leave a job suddenly because of a medical crisis and without an idea of when you might return can not only lead to rational concerns about financial security, but can cause significant anxiety and stress, lower self-esteem, and leave you dependent on others for care and support – perhaps for the first time since becoming an adult.

Returning to work after a long period of sickness absence can also present a challenge and might best be achieved on a phased-return, part-time, even voluntary basis until such time as you know you can handle its demands and don't experience any setbacks or relapses.

It is important that you know your employment rights and we hope this booklet will let you see how you can survive when ill-health leads to problems at work, and that it will be a good reference tool when you are in a position to return to work.

While we have tried to make the explanations as easy to understand as we can, many involve detail that might best be read and understood by someone who does not have the kind of cognitive challenges and energy restrictions that are caused by ME/CFS or Long Covid. We suggest that you try and read the booklet if able, but ask a family member, close friend, carer, or appointed representative to help you understand and interpret the content where necessary.

If you have any additional questions, please do not hesitate to contact ME Connect – the charity's support and information service:

- Telephone helpline (0808 801 0484). Visit our website to see opening times: **https://meassociation.org.uk/me-connect/**
- Email: meconnect@meassociation.org.uk,
- Social media private message: Facebook, Twitter, Instagram.

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It is important that you know your employment rights and we hope this booklet will let you see how you can survive when ill-health leads to problems at work, and that it will be a good reference tool when you are in a position to return to work.

STAY UP TO DATE

■ Rules and regulations and rates of payment for sickness allowances and welfare benefits usually change around the time of a new tax year i.e., from 06 April. The information included in this booklet was correct to 31 December 2023.

■ The UK Government website is a good resource for the latest information:

Working, jobs, and pensions.
http://tinyurl.com/h958c45a

Disabled people: carers, rights, benefits and Equality Act.
http://tinyurl.com/3sc9tkzt

Financial help if you are disabled.
http://tinyurl.com/48kev4wp

Benefits calculators.
http://tinyurl.com/5n7xsfa4

Become an appointee for someone claiming benefits.
http://tinyurl.com/y9vjdea2

Employment and Support Allowance.
http://tinyurl.com/4xcum9wz

Personal Independence Payment.
https://www.gov.uk/pip

Universal Credit.
http://tinyurl.com/mr2eykx4

■ ACAS provide a good review of the options available and your rights if you are absent from work due to ill-health or are disabled and able to work:

Checking sick pay.
http://tinyurl.com/yvm69p47

Fit notes and proof of sickness.
http://tinyurl.com/89beb4mu

Getting a doctor's report about an employee's health.
http://tinyurl.com/4d9uzy42

Supporting disabled people at work.
http://tinyurl.com/vk8bencs

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THE LAW AND DISABILITY

There is no need for a person to establish a medically diagnosed cause for their impairment. What is important is the effect that the impairment has on a person's ability to initiate and complete day-to-day activities.

1. Overview

■ The 2010 Equality Act legally protects you from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in certain situations.

■ It sets out the different ways in which it is unlawful to treat a person based on a range of 'protected characteristics' and one of these characteristics relates to disability.

■ A person is defined as disabled under the Act if he or she has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

■ The key parts of this definition are:

- **Physical or mental impairment:**

  ME/CFS and Long Covid can be considered as having either or both a physical and mental effect.

- **Substantial:**

  The focus should be on what a person is unable to do in terms of normal day-to-day activities.

- **Long term:**

  Means the effects have lasted, or are likely to last, for at least 12 months.

■ There is no need for a person to establish a medically diagnosed cause for their impairment. What is important is the effect that the impairment has on a person's ability to initiate and complete day-to-day activities.

■ In circumstances where a disabled employee is placed at a disadvantage by some feature or aspect of their employer's workplace or regime then the employer has a duty to consider 'reasonable adjustments' (see below) to cater to the needs of a disabled employee so that they might still be able to do their job.

■ ME/CFS is listed as an example covered by the Equality Act in the Government's guidance document (D5 below). If an employer is not willing to recognise any workplace disadvantage because of ME/CFS (or Long Covid) and make 'reasonable adjustments', this may be regarded as discrimination under the Act – in which case you might consult a union representative or consider taking legal advice.

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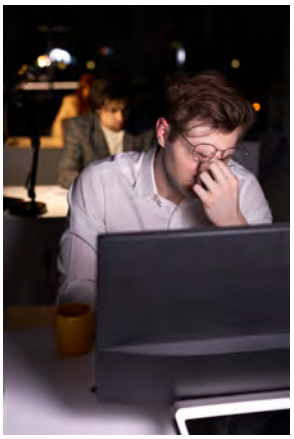
THE LAW AND DISABILITY

2: The 2010 Equality Act. Section A5

"A disability can arise from a wide range of impairments which can be [for example,] … impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression and epilepsy…"

Source: The 2010 Equality Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability (May 2011).

http://tinyurl.com/4m5jsbs7



How are symptoms such as debilitating fatigue, post-exertional malaise, sleep disturbance or unrefreshing sleep (or both), and orthostatic intolerance – an inability to remain standing for long – going to impact on your ability to perform a job?

RETURNING TO EMPLOYMENT

1. Overview

■ Most people with ME/CFS or Long Covid will find that some degree of improvement occurs over the course of time – but this may take longer than initially expected (years rather than months).

■ Once your health has stabilised and you have been able to increase activities comfortably and sustainably, it may be possible to attempt a return to work.

■ A sudden return to full-time work is often unrealistic. A far more sensible idea is to try and return on a very flexible and part-time or phased-return basis, possibly in a role that is less demanding both physically and mentally or one that has been adapted to accommodate your needs.

■ Any decision to return to work will have to take account of a number of factors relating to health and disability that will need to be carefully thought through and discussed with your employer. These might include:

- **Physical symptoms:**

  How are symptoms such as debilitating fatigue, post-exertional malaise, sleep disturbance or unrefreshing sleep (or both), and orthostatic intolerance – an inability to remain standing for long – going to impact on your ability to perform a job?

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RETURNING TO EMPLOYMENT

How will problems with 'brain fog', memory, concentration, information processing and retrieving, attention span, and focus affect your ability to work?

- **Cognitive symptoms:**

How will problems with 'brain fog', memory, concentration, information processing and retrieving, attention span, and focus affect your ability to work?

- **Mobility:**

ME/CFS and Long Covid can affect functional ability and mean that some people need to use a wheelchair or other walking aid and cannot mobilise easily or without the help of someone else. How will this affect your ability to commute, to get to work on time, and how will you be able to get around once you are at work?

- **Symptom variability:**

You might find that your symptoms are more manageable at certain times of day. If you function better in the afternoon, then see if your employer can accommodate afternoon working. If not, then see if you can arrange for a more flexible working arrangement and for a quiet place to rest when symptoms flare.

- **Fitness:**

  - Unless you have prepared yourself properly for a return to work, then it is very likely to test your level of fitness. You will probably have spent a long time convalescing and using activity management and pacing to help manage your limitations.

  - You might have only been able to perform basic activities and may not have been able to extend them to exercise and to other methods of building strength and stamina. You might still need periods of rest or sleep during the day.

  - Returning to work can also be a challenge socially and to your mental health, especially when you have been isolated for a long time.

  - Phased returns as part of any reasonable adjustments (below) might be preferable so that you can see how you will cope, and to help you decide if a return is the right move at this time. They would also enable you to determine what practical support you would need to help you remain in work.

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RETURNING TO EMPLOYMENT

- If your illness and functional ability has improved and remained stable at a manageable level for some time and if you have been able to improve your fitness and confidence, then these issues might not impact your work-related ability as much as they did before.

- However, it is often the case that you won't really know how you will cope until you try. Be prepared to review any unforeseen difficulties as they arise with your employer to see if accommodations can be made that help to keep you in work (see Reasonable Adjustments, and Employment and Support Allowance: Permitted Work, below).

If your illness and functional ability has improved and remained stable at a manageable level for some time and if you have been able to improve your fitness and confidence, then these issues might not impact your work-related ability as much as they did before.

2. Discussions with an existing employer

- Once you are clear in your own mind that a return to work is viable, you need to discuss it with your employer or human resources manager, preferably the occupational health (OH) department as well, and your union or professional organisation representative.

- A mutually agreed return to work plan can then be drawn up which takes account of your current state of health and its limitations, the variability of your illness, and that you may not be able to cope with some of the physical, mental, or social aspects of the role that you performed before your diagnosis.

- To start with this will almost certainly involve a significant reduction in hours and possibly duties as well. It may be wise to see if you can do an informal 'trial run' at work, with a few short sessions, before formalising the arrangement. You might find that with a large employer you can attempt a different, less demanding role, or work with someone who is completing the role you did before on a part-time or occasional basis.

- You also need to be clear as to how and when you expect you might be able to increase your working hours and/or responsibilities – and consider fallback options should you find the agreed plan to be too much. With ME/CFS or Long Covid it can be very hard predicting the future, so include plenty of time at each stage to ensure you are comfortable before taking on more work.

- There should be regular ongoing reviews that consider how you are coping and performing with both the Human Resources and OH departments. The 'return-to-work' plan should be mutually agreed and

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preferably be in writing, it should also have an in-built flexibility that allows for any setbacks to your health.

More information

Acas: Returning to work after absence.
http://tinyurl.com/3wf7seut

An employer cannot ask searching questions about your health as part of an application or interview process.

3. Medical disclosures

■ An employer cannot ask searching questions about your health as part of an application or interview process. However, they can ask if you can accomplish a task that is essential to the job, or whether any reasonable adjustments will need to be made for you to do that job. At the same time there is clearly no point in applying for a job that involves tasks you just can't manage because of your disability.

■ If you develop a disability while employed, you cannot be fired or made to resign, be chosen for redundancy, or be forced to retire because you have become disabled. Instead, your employer should discuss making reasonable adjustments (see below) to help you to plan a return to work or enable you to continue in work, when able.

■ If you have been asked a question about medical conditions in an application form or interview that is contrary to the Equality Act, you can inform the Equality and Human Rights Commission, who can investigate the matter and act if necessary.

■ If you have been subject to discrimination due to disclosure of your medical condition, you may be able to take a case to an Employment Tribunal. There is a three-month time limitation for claims, so you should seek the advice of an employment solicitor without delay if you find yourself in this situation.

■ There are some circumstances where an employer can ask reasonable questions about medical conditions once you become an employee. However, an employer must not use that information to then discriminate against you.

More information

Gov. UK: Equality Act 2010: What do I need to know? A quick start guide to the ban on questions about health and disability during recruitment.
http://tinyurl.com/erf7nr3w

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RETURNING TO EMPLOYMENT

If your symptoms impact your working ability, you cannot expect your employer to make any accommodations unless you tell them first. And, if your condition is bad enough to be deemed a disability, the employer then has a legal duty to make reasonable adjustments.

4. Reasonable adjustments

■ The 2010 Equality Act has determined that in circumstances where a disabled employee is placed at a disadvantage by some feature or aspect of their employer's workplace or regime then the employer has a duty to consider 'reasonable adjustments' to cater to the needs of a disabled employee so that they might still be able to do their job.

■ Reasonable adjustments at work could include flexible hours, modifications to duties, and the use of practical aids that assist or enable you to do the job you have been employed to do.

■ You can agree to let certain people at work know about your disability and sign a consent form to comply with the Data Protection Act. However, a duty to make adjustments at work obviously can't happen until an employer knows or ought reasonably to know that you are disabled.

■ While there is not an explicit duty on employers to enquire, the 2010 Equality and Human Rights Equality Act: Codes of Practice (below) suggests that employers must do all they can be reasonably expected to do to find out if an employee is disabled and in need of support.

■ Knowledge held for example by the occupational health or human resource departments may be inferred to the employer – so you don't need to advise them explicitly that you have ME/CFS or Long Covid if it doesn't affect your ability to work.

■ However, if your symptoms impact your working ability, you cannot expect your employer to make any accommodations unless you tell them first. And, if your condition is bad enough to be deemed a disability, the employer then has a legal duty to make reasonable adjustments.

5. The 2010 Equality and Human Rights Act: Codes of Practice

6.17: An employer only has a duty to make an adjustment if they know, or could reasonably be expected to know, that a disabled person is, or may be, an applicant for work.

6.19: For disabled workers already in employment, an employer only

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RETURNING TO EMPLOYMENT

has a duty to make an adjustment if they know, or could reasonably be expected to know, that a worker has a disability and is, or is likely to be, placed at a substantial disadvantage. The employer must, however, do all they can reasonably be expected to do to find out whether this is the case. What is reasonable will depend on the circumstances. This is an objective assessment. When making enquiries about disability, employers should consider issues of dignity and privacy and ensure that personal information is dealt with confidentially.

6.20: The Act does not prevent a disabled person keeping a disability confidential from an employer. But keeping a disability confidential is likely to mean that unless the employer could reasonably be expected to know about it anyway, the employer will not be under a duty to make a reasonable adjustment. If a disabled person expects an employer to make a reasonable adjustment, they will need to provide the employer – or someone acting on their behalf – with sufficient information to carry out that adjustment.

Source: The 2010 Equality and Human Rights Act: Employment Statutory Code of Practice, Chapter 6, Duty to make reasonable adjustments, page 78. **http://tinyurl.com/yc86758r**

Reasonable adjustments could include flexible working – where you agree to a set number of hours but can be flexible about when you choose to work them.

6. Practical adjustments

■ Reasonable adjustments and modifications could include any of the following:

- Adjusting business premises to allow for greater accessibility e.g., should you need wheelchair access or have difficulty climbing stairs, or need more space in your work area, or somewhere that is quiet to rest.
- Assigning a different place of work e.g., a quieter area of the office, or allowing you to work from home during a period of rehabilitation, or for certain days of the week, or on a part-time or permanent basis.
- Transferring a disabled member of staff to fill another vacancy, e.g., a sales representative who has had to give up driving could be transferred to an office-based position.
- Adjusting working hours to give a later or earlier start to the working day or allowing for longer lunch breaks and a later finish. Or allowing flexible working – where you agree to a set number of hours but can be flexible about when you choose to work them.

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Allocating some of the duties that your role would normally involve to someone else who might be better able to complete them – this could involve a formal 'job-share' arrangement.

- Allowing time off for rehabilitation or medical treatment (see Disability Leave, below).
- Allocating some of the duties that your role would normally involve to someone else who might be better able to complete them – this could involve a formal 'job-share' arrangement.
- Arranging or allowing for extra training on a one-to-one basis that might be more conducive to your needs.
- Acquiring or modifying equipment, e.g., installing disability software on a computer that allows greater accessibility, or an ergonomic chair, or wheelchair- adapted desk.
- Providing supervision, e.g., a mentor or support worker who can help when you experience difficulties and complete tasks or share the workload.
- Modifying reference manuals, e.g., providing oral instructions as an alternative to written instructions, or using text-reading software.

More examples

The 2010 Equality and Human Rights Act: Employment Statutory Code of Practice, 6.32 page 86:
http://tinyurl.com/yc86758r

7. Benefits and government help

■ Returning to work will affect whether you are eligible to continue claiming some benefits. The ways in which it will do this depend on the benefit you are claiming.

a. Benefits

i. Universal Credit (UC)

■ Unlike ESA, there are no set rules for UC on how much you can work while claiming. Instead, if you have been assessed as having limited capability for work, you can work as much as you would like, and your UC payment will be reduced as your earned income increases.

■ If you have been given a Limited Capability for Work or Limited Capability for Work Related Activity status following your Work Capability Assessment, then this will stay with you on your claim until you are reassessed.

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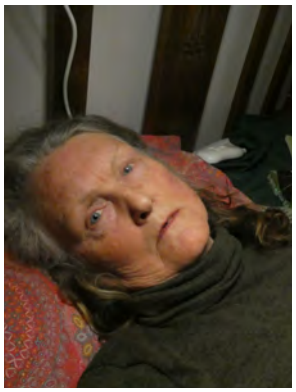

If the DWP decide you no longer meet the criteria for having Limited Capability for Work, then your status will be amended on your Universal Credit claim.

- You do have a duty to report any change in your health status, so if you feel you are well enough to resume employment then you need to report this in your online journal.

- The amount of Universal Credit you receive is dependent on household income and is reassessed monthly so if you begin to earn, this will impact on the amount of benefit received.

- If the DWP decide you no longer meet the criteria for having Limited Capability for Work, then your status will be amended on your Universal Credit claim. You are able to report any further changes of circumstance in your online journal so if you find that work is more of a struggle, you can request another Work Capability Assessment.

ii. Employment and Support Allowance (ESA): Permitted Work

- If you are claiming New-Style ESA and feel able to return to work in some capacity, you might want to try the Permitted Work option before giving up your benefit completely.

- Reapplying for ESA if you find employment too demanding, can be much more of a challenge, while Permitted Work gives you extra flexibility.

    - Permitted work can help you learn new skills, build your confidence and start thinking about types of work you could do.

    - If you have a disability, illness, or health condition you may be able to do some work and keep your payments and National Insurance credits for Employment and Support Allowance (ESA).

    - Permitted work means you can:

        - work for less than 16 hours each week.

        - earn no more than £167.00 each week, after tax and National Insurance has been taken off.

        - get your normal amount of benefit.

        - build up your skills and experience.

        - be supported while you work – we call this supported permitted work.

    - There is no limit on the number of weeks you can do permitted, or support permitted work for.

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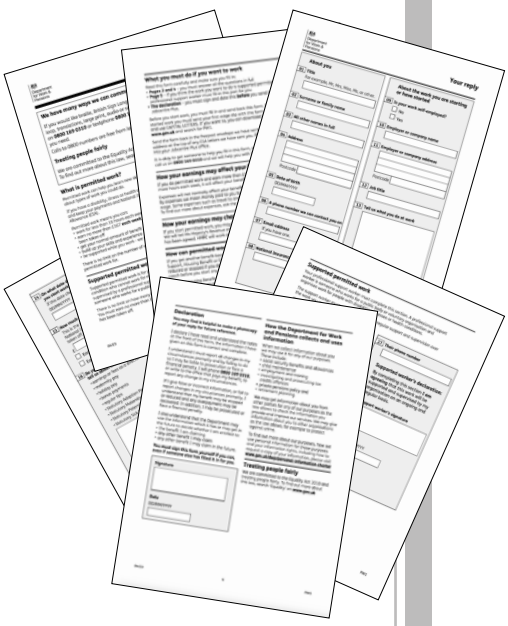
RETURNING TO EMPLOYMENT



Before you start any work, you must fill in a permitted work PW1 form and post it to the address at the top of any ESA letters we have sent you.

- Before you start any work, you must fill in a permitted work PW1 form and post it to the address at the top of any ESA letters we have sent you. Please do not take this form into your Jobcentre Plus office.

http://tinyurl.com/5n6mn5w8

- If you think the work you want to do is supported permitted work, your professional support worker must fill in their section on the permitted work PW1 form.

- The DWP will tell you if the work you want to do meets the permitted work conditions. If you do work that does not meet the conditions, you could lose your benefit.

- If you get another benefit because you are not working (for example Income Support, Housing Benefit or Council Tax Reduction), then your benefit may be reduced or stopped if you do any work. Please talk to your Jobcentre Plus work coach before you start any work.

- If you get Housing Benefit or Council Tax Reduction and you are thinking of starting permitted work, you must talk to your local authority straight away, as the amount you get may change.

Source: Gov.UK: Permitted Work Factsheet.
http://tinyurl.com/42am6xv2

iii. Personal Independence Payment (PIP)

- Claims for PIP are not means-tested, so it is perfectly reasonable to continue your claim while working if you have a health condition or disability that continues to affect you.

- However, be aware that your ability to work may be considered as evidence against your claim if it reflects an improvement in your health and contradicts what you have stated during your benefit application or at the last review. If you are working, and are asked about this at a PIP assessment, be clear about any adjustments which have been made to allow you to work, and any impact working has on your symptom severity

- You have a duty to report any changes and the DWP may decide to reassess your claim based on any new information you provide.

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RETURNING TO EMPLOYMENT

Access to Work can help you get or stay in work if you have a physical or mental health condition or disability.

b. Government help

■ There are various types of practical and financial help available from government agencies to help people return to work after a long sickness absence and if they are disabled. Examples include:

i. Access to Work:

- Access to Work can help you get or stay in work if you have a physical or mental health condition or disability.
- The support you get will depend on your needs. Through Access to Work, you can apply for:
  - a grant to help pay for practical support with your work.
  - support with managing your mental health at work.
  - money to pay for communication support at job interviews.
- Check you are eligible and then apply for an Access to Work grant.

Check eligibility: **http://tinyurl.com/4earxh57**
Apply for an Access to Work grant: **http://tinyurl.com/4wstrpff**

Source: Gov.UK: Access to Work.
http://tinyurl.com/5n8yzje8

ii. Work and Health Programme:

- The Work and Health Programme helps you find and keep a job if you're out of work.
- You do not have to be getting benefits to apply.
- You'll get personal support to help you:
  - identify your employment needs.
  - match your skills to work that's available.
  - put you in touch with employers.
  - find long-term employment.
  - get training to help you find work.

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RETURNING TO EMPLOYMENT

The Work and Health Programme helps you find and keep a job if you're out of work.

- manage health problems to reduce their impact on work.

- Ask your work coach if you're eligible. They will apply for you.

- If you don't have a work coach, go to your local Jobcentre Plus and ask to speak to a work coach about the Work and Health Programme:

http://tinyurl.com/2k55sx92

Source: Gov.UK: Work and Health Programme.
http://tinyurl.com/mr3wm7yn

8. The Health Adjustment Passport (HAP)

■ The Health Adjustment Passport (HAP) can be a very helpful tool to support employees with a disability or health condition that makes it harder for you to move into work or stay in a job.

■ The HAP belongs to you, and it cannot be shared with others without your permission, although you might want to use it when in discussion with your employer and negotiating reasonable adjustments, for example.

■ It should be used as a 'living document' and regularly reviewed to check if any adjustments remain appropriate, and updated accordingly when your role changes or you move to a different employer.

■ It can be used to:

- help you identify the support and changes (reasonable adjustments) you may need when you are in work or moving into work.

- apply for support from Access to Work (see above). This could include funding for specialist equipment to support you to do your job, support getting to and from work or support when you are in work, such as job coaching.

- help you talk to employers about adjustments and in-work support that you may need.

■ A job could also include self-employment, an apprenticeship, volunteering, work experience or a supported internship.

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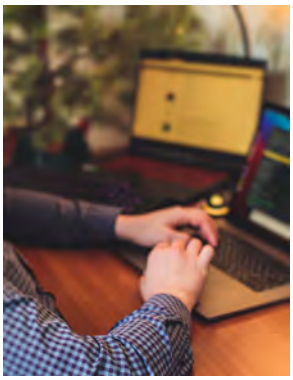
RETURNING TO EMPLOYMENT



ME/CFS or Long Covid might allow you to keep working, although you will probably need to reduce hours or rearrange your life to allow time to rest in the evenings and at weekends.

Source: Gov.UK: The Health Adjustment Passport.
http://tinyurl.com/z82a2n5a

More information

The Health Adjustment Passport Template:
http://tinyurl.com/4yp9jfn9

EMPLOYMENT AND SICKNESS

1. Ill-health: the early stages

a. Overview

■ You are most likely to have developed ME/CFS following an acute infection (although there are other known triggers) that affected your ability to function normally. Long Covid will have been triggered by the Covid-19 virus. Both conditions can cause similar symptoms and ongoing disability that will likely affect your ability to work.

■ ME/CFS or Long Covid might allow you to keep working, although you will probably need to reduce hours or rearrange your life to allow time to rest in the evenings and at weekends. But most people will experience a moderate to severe form of disability at some point, and this is more likely to render them unable to work.

■ A lack of early intervention could mean that you try to stay in work or return to work feeling very unwell when you should be having a good period of convalescence and doing all you can to accept, to adapt, and to accommodate your change in circumstance.

■ If bad advice or a lack of good advice is then followed by a series of erratic attempts at working, and more sick leave, anecdotal evidence suggests that this can significantly increase the risk of your condition becoming more severe and persistent. The risk of relapse can also be increased by returning to work prematurely and without any accommodations in place.

■ We recognise there is often a pressing need to return to work and that you might go beyond what is otherwise sensible. This can happen when you don't receive appropriate medical advice or because you consider working and receiving an income to be a greater priority than taking good care of yourself.

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EMPLOYMENT AND SICKNESS

■ Sometimes it can be because you simply want to test your abilities or because an employer has made 'reasonable adjustments' (see above) to a role to try and accommodate your disability, or alternatively because a demanding employer is making life difficult, and you feel you need to return to keep your job.

More information

Gov.UK: What to do if you become disabled.
http://tinyurl.com/kyb47d4v

b. The NICE Guidelines

■ The National Institute for Health and Care Excellence (NICE) use the best available evidence to develop recommendations that guide decisions in health, public health and social care. National Guidelines are produced on a range of medical conditions including ME/CFS and Long Covid.

■ The NICE Guideline on ME/CFS is endorsed by the ME Association and is comprehensive set of recommendations. The NICE Guideline on Long Covid is evolving and subject to periodic change as the evidence base develops.

■ The Guidelines explain what to expect from the NHS – GPs, ME/CFS Specialist Services and Long Covid Clinics – and Social Care Services who provide help and support at home.

■ ME/CFS and Long Covid can be suspected 6 weeks after symptoms develop, and a diagnosis should be made within 3 months. A GP should then refer you to an ME/CFS Specialist Service or Long Covid Clinic.

■ It may take longer in practice before a diagnosis is given which can mean referrals to hospital-based secondary care services can be delayed, and you might not receive the best advice in a timely fashion.

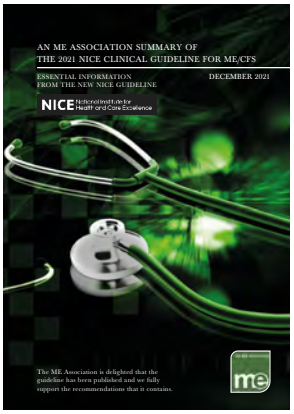
■ You might find that there are no ME/CFS Specialist Services or Long Covid Clinics in your area, or that you cannot access them because, for example, you experience difficulty traveling.

■ Not all secondary care services are able to offer home visits or remote access (although this is a Guideline recommendation), but you should try and determine if they do.

The ME Association features the NICE Guidelines on its website in an accessible format for reference purposes and a full range of free literature written by topic experts on ME/CFS and Long Covid. You can also search for NHS ME/CFS specialist services and Long Covid clinics and Local Support Groups.

Please visit website to learn more:

https://meassociation.org.uk



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EMPLOYMENT AND SICKNESS

A GP, ME/CFS Specialist Service, or Long Covid Clinic should refer you to social care services if you need help at home.

More Information

You will find both NICE Guidelines on the ME Association website, and can also locate your nearest specialist service or clinic. You can also visit the NICE website and download the guidelines in full:

- The NICE Guideline on ME/CFS:

https://www.nice.org.uk/guidance/ng206

- The NICE Rapid Guideline on Long Covid:

https://www.nice.org.uk/guidance/ng188

- You could be dependent on the services offered by a GP, but primary care services should still be able to facilitate the recommendations made in the relevant Guideline with help from community health and social care providers.

- NICE Guidelines provide evidence-based recommendations on symptom and illness-management and detail the support you should expect from NHS and social care services. The recommendations also include help with employment and welfare benefits.

- A GP, ME/CFS Specialist Service, or Long Covid Clinic should refer you to social care services if you need help at home. You can also self-refer to your local authority social care service. You will need to have a care needs assessment that is likely to involve a home visit. The NHS can also help if you need support when in negotiation with your employer about the need for sick leave, reduced hours, or a return to work etc. and either NHS or social care services should facilitate any need you might have for disability aids and adaptations.

- Whether or not you have access to an ME/CFS Specialist Service or Long Covid Clinic, the recommendations in the NICE Guidelines are just as relevant to the healthcare you should receive, and we strongly suggest that you familiarise yourself with the relevant Guideline and discuss it with your health and social care provider.

c. Talk to your employer

- It is important to keep in touch with your employer, line manager, human resources, and any occupational health (OH) department about health-related issues that affect your ability to work at the earliest opportunity.

- If you belong to a union or professional body, then keep paying subscriptions if you can – you may well need their help later.

- You or your representative should carefully review your employment contract and how it relates to e.g., sickness absence, sick pay, and ill-health early retirement.

- Keeping in regular contact with your employer might generate feelings of anxiety, but it is better that you keep them aware of your situation and provide any necessary documentation e.g., fit notes from your GP, to maintain a good relationship.

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EMPLOYMENT AND SICKNESS

If you are too unwell to apply for benefits, then a relative or friend can be appointed to deal with benefits on your behalf.

■ An employer will often want to make regular enquiries if you are on a prolonged period of sick leave, and this may involve arranging for someone to come and see you at home. While this can add pressure to an already difficult situation, it is important that you or your representative try and keep them informed, even if there hasn't been any improvement.

d. Representation

■ If you are too unwell to apply for benefits, then a relative or friend can be appointed to deal with benefits on your behalf:

http://tinyurl.com/y9vjdea2

■ If you find it difficult to understand your care and support needs, find it hard to speak up, or don't have a relative or friend who can represent you, there are people who can help:

http://tinyurl.com/2n3ytuya

■ Citizen's Advice provide a good overview of the options available if you need to appoint someone to manage your affairs because of illness or disability, including how to establish a power of attorney:

http://tinyurl.com/4seek6uy

e. Summary

■ Keep in touch with your GP and social care provider (if you need help at home), arrange appropriate care and support, discuss income and employment concerns, and download and refer to the relevant NICE Guideline (see above).

■ Obtain good, personalised management and employment advice from an NHS ME/CFS Specialist Service or Long Covid Clinic. If you are severely or very severely affected, then preferably one that can visit you at home or that offers remote access and can liaise with your representative if you are too unwell.

■ Establish a Care and Support Plan with your GP, ME/CFS Specialist Service or Long Covid Clinic, and social care provider (see recommendation in the NICE Guideline) and arrange regular reviews with your GP.

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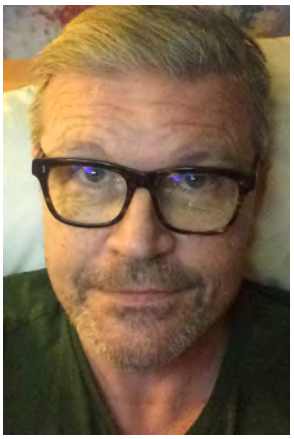

Avoid trying to return to work if you are not well enough to do so. If you do feel able to return in some capacity, then talk to your GP and employer about making 'reasonable adjustments' to your role and workspace to better accommodate any continuing disability.

■ Consider any relevant welfare benefits and make an application as soon as you – or your representative – is able. Employment and Support Allowance, Universal Credit, and Personal Independence Payment are the main related benefits (see below).

■ Keep in touch with your employer and complete and return any necessary documentation relating to sick leave as soon as possible (see below).

■ Avoid trying to return to work if you are not well enough to do so. If you do feel able to return in some capacity, then talk to your GP and employer about making 'reasonable adjustments' to your role and workspace to better accommodate any continuing disability (see below).

■ If you are too unwell or feel unable to adequately explain your needs to healthcare professionals or when applying for benefits and attending medical assessments, options are available that can help (see, Representation, above).

2. Sick Leave and Fit Notes

a. Sick Leave

● Employees can take time off work if they're ill. You can also claim sick pay if you are on a casual, short term, zero hours or agency contract, as long as the following conditions apply:

1. You have an employment contract
2. You have done some work under this contract
3. You earn an average of at least £123 per week

● They need to give their employer proof if they're ill for more than 7 days.

● If they're ill just before or during their holiday, they can take it as sick leave instead.

b. Proof of sickness

■ Doctors issue fit notes to people that provide evidence of the advice they have given about their fitness for work. It records details of the functional effects of their patient's condition so the patient and their employer can consider ways to help them return to work – once a return to work has been judged feasible.

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EMPLOYMENT AND SICKNESS

Employees must give their employer a 'fit note' (sometimes called a 'sick note') if they've been ill for more than 7 days in a row and have taken sick leave.

- Employees must give their employer a 'fit note' (sometimes called a 'sick note') if they've been ill for more than 7 days in a row and have taken sick leave. This includes non-working days, such as weekends and bank holidays.
- The fit note will say the employee is either 'not fit for work' or 'may be fit for work'.
- If it says the employee 'may be fit for work', employers should discuss any changes that might help the employee return to work (for example, different hours or tasks). The employee must be treated as 'not fit for work' if there's no agreement on these changes.
- Employers can take a copy of the fit note. The employee should keep the original.

c. Getting a Fit Note

- Employees can get a fit note from the following healthcare professionals:
  - GP or hospital doctor.
  - Registered nurse.
  - Occupational therapist.
  - Pharmacist.
  - Physiotherapist.
- The healthcare professional needs to assess the employee's fitness for work before giving a fit note.
- Fit notes are free if the employee has been ill for more than 7 days when they ask for one. The healthcare professional might charge a fee if the employee has been ill for 7 days or less.

d. Self-certification

- If employees are off work for 7 days or less, they do not need to give their employer a fit note or other proof of sickness from a healthcare professional.
- When they return to work, their employer can ask them to confirm they've been off sick. This is called 'self-certification'.

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Employers must make changes to an employee's working conditions if they're disabled. These changes are known as 'reasonable adjustments' and could include adapting equipment employees use at work.

EMPLOYMENT AND SICKNESS

- The employer and employee will agree on how the employee should do this. They might need to fill in a form or send details of their sick leave by email.

e. Returning to work

- Employers must make changes to an employee's working conditions if they're disabled. These changes are known as 'reasonable adjustments' (see above) and could include working shorter hours or adapting equipment employees use at work.
- Employees can get advice from ACAS (see above) on managing health conditions at work and returning to work from sick leave.

Source: Gov UK: Taking Sick Leave.
http://tinyurl.com/ybfseecn

Source: British Medical Association: Issuing Fit Notes.
http://tinyurl.com/ymyr7mkx

3. Sick Pay

a. Statutory Sick Pay (SSP)

i. Overview:

- You can get £109.40 per week Statutory Sick Pay (SSP) if you're too ill to work and are eligible:
  - you cannot get less than the statutory amount.
  - You can get more if your company has a sick pay scheme (or 'occupational scheme') – check your employment contract.
- SSP is paid by your employer for up to 28 weeks.
- You can get SSP from the 4th day you're off sick.
- There are different sick pay rules for agricultural workers.
- There's a separate guide on Statutory Sick Pay if you're an employer.
- SSP is paid by your employer in the same way as your normal wages, for example weekly or monthly.

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EMPLOYMENT AND SICKNESS

- If you have more than one job, you may get SSP from each employer.
- Tax and National Insurance will be deducted.

ii. Eligibility:

- To qualify for SSP you must:
  - be classed as an employee and have done some work for your employer.
  - earn an average of at least £123 per week.
  - have been ill for at least 4 days in a row (including non-working days).
- How many days you can get SSP for depends on why you are off work.
- You must usually tell your employer you're unable to work before the deadline they set (or within 7 days if they have not set one). You could lose some of your SSP if you do not tell your employer in time.
- You will not qualify for SSP if you:
  - have received the maximum amount of SSP (28 weeks).
  - are getting Statutory Maternity Pay.
- You can still qualify if you started your job recently and you have not received 8 weeks' pay yet. Ask your employer to find out more.

iii. Linked periods of sickness:

- If you have regular periods of sickness, they may count as 'linked'. To be linked, the periods must:
  - last 4 or more days each.
  - be 8 weeks or less apart.
- You're no longer eligible for SSP if you have a continuous series of linked periods that lasts more than 3 years.

You must usually tell your employer you're unable to work before the deadline they set (or within 7 days if they have not set one). You could lose some of your SSP if you do not tell your employer in time.

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EMPLOYMENT AND SICKNESS

iv. If you're not eligible or your SSP ends:

- You may be able to apply for Universal Credit or Employment and Support Allowance (ESA) (see below). You can use form SSP1 to support your application.
- If your SSP is ending your employer must send you form SSP1 either:
  - within 7 days of your SSP ending if it ends unexpectedly while you're still sick.
  - on or before the beginning of the 23rd week, if your SSP is expected to end before your sickness does.
- If you do not qualify for SSP your employer must send you form SSP1 within 7 days of you going off sick.

Source: Gov UK: Statutory Sick Pay.
http://tinyurl.com/4sp2v7hc

b. Sick pay from employment

- Some employers are reasonably generous with their own sick pay schemes.
- They can keep paying a percentage of normal salary for a period (which may extend to 6 months) after SSP has expired, and then a reduced percentage for another period (which may be up to a year).
- But other employers are not. It is well worth checking the small print in your employment contract or getting someone to do it for you, if a prolonged period of sick leave seems likely, and then discussing the matter with your employer.
- Some unions also have hardship funds available for members experiencing financial difficulties as a result of ill-health and disability.

Some employers are reasonably generous with their own sick pay schemes.

They can keep paying a percentage of normal salary for a period (which may extend to 6 months) after SSP has expired, and then a reduced percentage for another period (which may be up to a year).

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EMPLOYMENT AND SICKNESS

The ME Association has a full range of literature about benefits including case studies and tips relating to ME/CFS.

6. Benefits and financial support

a. Overview

■ If you're not already claiming any benefits – or even if you are – then we recommend you use one of the approved benefits calculators to see which of the benefits you might (also) be entitled to receive:

Gov.UK: Benefits Calculators:
http://tinyurl.com/5n7xsfa4

■ The ME Association has a full range of literature about benefits including case studies and tips relating to ME/CFS, available to download from the website shop:

ME Association: Benefits Guides:
https://meassociation.org.uk/iqgm

■ There is a wide range of disability-related financial support, including benefits, tax credits, payments, grants and concessions. Some benefits you might receive are:

- Universal Credit.
- Employment and Support Allowance (ESA).
- Personal Independence Payment (PIP).
- Attendance Allowance.

Gov.UK Financial help if you are disabled: **http://tinyurl.com/48kev4wp**

b. Universal Credit (UC)

- Universal Credit is a means-tested payment to help with your living costs. It's paid monthly - or twice a month for some people in Scotland. You may be able to get it if you're on a low income, out of work or you cannot work due to ill-health or disability.
- You can receive UC as well as Personal Independence Payment (PIP) or Carer's Allowance (CA) if you are eligible for them.
- You might get an extra amount of Universal Credit if you have a health condition or disability that limits how much work you can do or if you cannot work.

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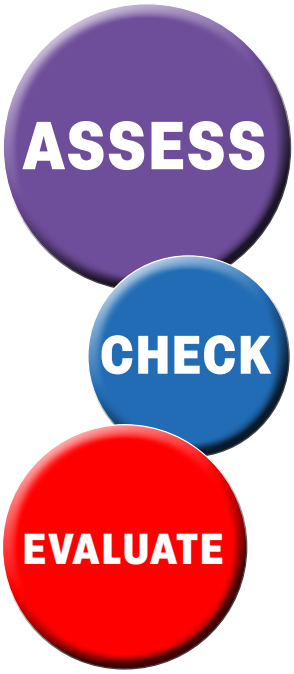

You'll be told if you need a Work Capability Assessment (WCA). The assessment is to decide how much your illness or disability limits your capability to work.

- Your monthly payment is based on your circumstances, for example your health condition or disability, income and housing costs.
- When you apply for Universal Credit, you can report if you have a health condition or disability that affects your capability to work. You'll need to provide a fit note (see above) and complete a 'Capability for Work' (UC50) health questionnaire.
- You'll be told if you need a Work Capability Assessment (WCA). The assessment is to decide how much your illness or disability limits your capability to work. If you need an appointment, you'll get a letter telling you what you need to do.
- The WCA can be in person, by video call or on the phone, and you can have someone else with you, for example a friend or support worker. It can also be recorded.
- Until a decision can be made on your WCA, you'll either:
  - get the standard allowance if you're making a new claim.
  - continue getting the same Universal Credit amount if you're reporting a change of circumstances.
- If the DWP determine that you have Limited Capability for Work Related Activity, because of your health condition or disability, you should receive an enhanced monthly payment in addition to the standard allowance.

More information

Gov.UK: Universal Credit:

http://tinyurl.com/mr2eykx4

The ME Association has a guide to making an application for UC if you have ME/CFS:

https://meassociation.org.uk/h6ha

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EMPLOYMENT AND SICKNESS

You can apply for Employment and Support Allowance (ESA) if you have a disability or health condition that affects how much you can work.

c. Employment and Support Allowance (ESA)

- You can apply for Employment and Support Allowance (ESA) if you have a disability or health condition that affects how much you can work. ESA provides:
  - money to help with living costs if you're unable to work.
  - support to get back into work if you're able to.
- You can apply if you're employed, self-employed or unemployed, are under State Pension age and you have a disability or health condition that affects how much you can work. You also need to have:
  - worked as an employee or have been self-employed, and have,
  - paid enough National Insurance contributions (see below), usually in the last 2 to 3 years (National Insurance credits also count).
- You can apply for New Style ESA up to 3 months before your SSP ends. You'll start getting New Style ESA as soon as your SSP ends.
- When you apply for ESA, you can report if you have a health condition or disability that affects your capability to work. You'll need to provide a fit note (see above) and complete a 'Capability for Work' (ESA50) health questionnaire.
- You'll be told if you need a Work Capability Assessment (WCA). The assessment is to decide how much your illness or disability limits your capability to work. If you need an appointment, you'll get a letter telling you what you need to do.
- The WCA can be in person, by video call or on the phone, and you can have someone else with you, for example a friend or support worker. It can also be recorded.
- If you are entitled to ESA, you'll be placed in one of 2 groups:
  - a work-related activity group (you cannot work now, but can prepare to work in the future, for example by writing a CV).

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EMPLOYMENT AND SICKNESS

- a support group (you cannot work now, and you're not expected to prepare for work in the future).

- The support group recognises the severity of your illness or disability and pays an additional amount of money on top of the basic amount of ESA.

- New Style and contribution-based ESA last for 365 days if you're in the work-related activity group.

You can prepare for work in the future, for example by writing a CV.

- There's no time limit if you're in the support group, or if you're getting income-related ESA.

- To keep getting ESA you must report any change in your circumstances. You may also need to send fit notes regularly.

More information

Gov.UK: Employment and Support Allowance.
http://tinyurl.com/4xcum9wz

The ME Association has a Guide to making an application for ESA if you have ME/CFS.
https://meassociation.org.uk/h6ha

d. Personal Independence Payment (PIP)

- Personal Independence Payment (PIP) can help with extra living costs if you:

  - have a long-term physical or mental health condition or disability, and,

  - have difficulty doing certain everyday tasks or getting around because of your condition.

- You can get PIP even if you're working, have savings or are getting most other benefits.

- You must be over 16 to apply and expect the difficulties you have to last for at least 12 months from when they started.

- There are 2 parts to PIP:

  - a daily living part – if you need help with everyday tasks.

  - a mobility part – if you need help with getting around.

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EMPLOYMENT AND SICKNESS

- Whether you get one or both parts and how much you get depends on how difficult you find everyday tasks and getting around. It is not dependent on your medical diagnosis.

- **Daily living part:**

You might get the daily living part of PIP if you need help with:

  - preparing food.
  - eating and drinking.
  - managing your medicines or treatments.
  - washing and bathing.
  - using the toilet.
  - dressing and undressing.
  - reading.
  - managing your money.
  - socialising and being around other people.
  - talking, listening and understanding.

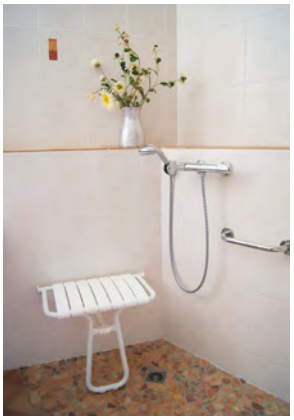
- **Mobility part:**

You might get the mobility part of PIP if you need help with:

  - working out a route and following it.
  - physically moving around.
  - leaving your home.
  - You do not have to have a physical disability to get the mobility part. You might also be eligible if you have difficulty getting around because of a cognitive or mental health condition, like anxiety.

- The Department for Work and Pensions (DWP) will assess how difficult you find daily living and mobility tasks. For each task they'll look at:

  - whether you can do it safely.
  - how long it takes you.



You might get the daily living part of PIP if you need help with daily functions, including washing, bathing and using the toilet.

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You might get the mobility part of PIP if you need help with working out a route and following it, physically moving around or leaving your home.

- how often you are able to do the task.
- whether you need help to do it from another person or by using extra equipment.

- Your carer could get Carer's Allowance if you have substantial caring needs:

http://tinyurl.com/vvw8unez

- If you live in Scotland, you'll need to apply for Adult Disability Payment (ADP) instead of PIP:

http://tinyurl.com/32c7w9uj

More information

Gov.UK: Personal Independence Payment (PIP):
https://www.gov.uk/pip

The ME Association has a Guide to making an application for PIP if you have ME/CFS:
https://meassociation.org.uk/7j8e

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NATIONAL INSURANCE AND STATE PENSION

When working, you pay National Insurance Contributions (NICs) to qualify for certain benefits and for a state pension when you reach your state pension age. It's not something we tend to think about when sick, but what happens when you are not able to work and how are your entitlements affected?

1. Overview

■ When working, you pay National Insurance Contributions (NICs) to qualify for certain benefits and for a state pension when you reach your state pension age. It's not something we tend to think about when sick, but what happens when you are not able to work and how are your entitlements affected?

■ Your state pension can be affected if there are gaps in your national insurance record. You need 10 qualifying years' worth of NICs to be eligible for a minimum state pension, and 35 qualifying years to receive a full state pension (if you reach state pension age after April 2016). The amount you receive will be based on the number of qualifying years you have made.

- If you earn a minimum (specified) amount of money and pay the required NICs during a tax-year (6 April to 5 April) then this will count as a qualifying year in terms of your eligibility for a state pension.
- It doesn't matter if you are able to work full-time on a good salary, or on the minimum wage, or for just a few days a week throughout the year; so long as you meet the qualifying criteria.
- Qualifying years can be from employment before or after 6 April 2016 and don't have to be consecutive.
- If you are sick or disabled and received certain welfare benefits, then 'national insurance credits' will be paid for you, and they will count towards your qualifying years – see below.

2. Voluntary National Insurance Contributions

■ If you are unable to work because of ME/CFS – which for most people is a long-term condition and is likely to affect your employment record – there may still be periods when you are receiving an income. For example:

- From a private disability pension or some form of illness protection insurance.
- You might not think about the long-term prospect of a state pension, but you could consider making voluntary NICs to maintain your eligibility. These can be paid whether you are in work or not and can also be used to cover gaps in your national insurance record normally for any period in the last 6 years.

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NATIONAL INSURANCE AND STATE PENSION

It is worth taking some time to check on your national insurance record to see when you might receive a state pension, the amount you qualify for, and how many years' worth of contributions you still need to make.

■ You might not think about the long-term prospect of a state pension, but you could consider making voluntary NICs to maintain your eligibility. These can be paid whether you are in work or not and can also be used to cover gaps in your national insurance record normally for any period in the last 6 years.

- Before you consider making voluntary contributions you should contact the Government's Future Pensions Centre. Telephone: 0800 731 0175.
- Explain your situation and they should be able to advise you about the best way to proceed and can also produce a state pension forecast.

■ It is worth taking some time to check on your national insurance record to see when you might receive a state pension, the amount you qualify for, and how many years' worth of contributions you still need to make.

- Use one or more of the links below, or you can contact the Future Pensions Centre on the telephone number above to find out more.

More information

Gov.UK: Check your state pension age:
http://tinyurl.com/yc4ev97r

Gov.UK: Check your national insurance record:
http://tinyurl.com/bdhw2vpn

Gov.UK: Check your state pension forecast:
http://tinyurl.com/mschy8de

Gov.UK: National Insurance: Help if you're not working:
http://tinyurl.com/3hsjdzf6

Gov.UK: Voluntary National Insurance Contributions (NICs) :
http://tinyurl.com/2t5zc5pb

3. National Insurance Credits

■ If your only or main source of income is sickness-related welfare benefits, then certain benefits (those aimed at replacing lost earnings) will provide national insurance credits.

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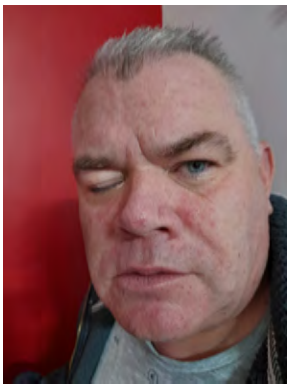
NATIONAL INSURANCE AND STATE PENSION



Ill-health early retirement ('medical retirement') is when you draw a private or workplace pension before the age of 55 (or the scheme's ordinary retirement date) due to permanent ill-health or disability.

■ These help you meet your qualifying years and ensure you are more likely to receive a state pension. Sometimes these credits are awarded automatically, sometimes you need to apply for them. However, not all sickness-related benefits are eligible.

■ For Example: Personal Independence Payment (PIP) is not eligible for credits. If your only source of income is PIP, then you might want to think about making voluntary contributions to maintain your state pension entitlement or apply for Employment and Support Allowance or Universal Credit, if you are eligible, as these do attract credits.

■ National Insurance credits are also available to:

- carers of people who are sick or disabled.
- parents with children who are or are not sick or disabled.
- family members who care for a child under 12.

More information

Gov.UK: National Insurance Credits - Check your eligibility: **http://tinyurl.com/bd5h8wdk**

ILL-HEALTH EARLY RETIREMENT

1. Overview

■ Ill-health early retirement ('medical retirement') is when you draw a private or workplace pension before the age of 55 (or the scheme's ordinary retirement date) due to permanent ill-health or disability.

■ To make a successful claim, it needs to be established that you can no longer continue to work in your normal role, or in another role that seriously reduces your earning potential. You'll need supportive medical evidence if you want to make a claim for medical retirement.

■ You can then start drawing a regular income and/or lump sum from your pension at the age that has been agreed, normally until you die, while retaining any after-death benefits for your spouse or next of kin.

■ In cases of serious ill health where your life expectancy is less than one year, you might be able to take all your pension as a tax-free lump sum.

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ILL-HEALTH EARLY RETIREMENT

Different pension schemes have different rules, so ask your pension provider or scheme administrator for details. Some allow you to access your pension early if it looks as if you won't be able to return to your job due to physical or mental illness.

■ If you have Income Protection Insurance (see above), you need to seriously consider whether to access your pension early. This is because any income you get from your pension could reduce the payments from the income protection plan.

■ The pension pot that you build up will probably be smaller if you retire early, because it's had less time to increase in value. You might be able to get higher payments if you need to take your pension early because of ill-health or disability.

■ Different pension schemes have different rules, so ask your pension provider or scheme administrator for details. Some allow you to access your pension early if it looks as if you won't be able to return to your job due to physical or mental illness. Other schemes might require that you won't be able to do any job, not just your own.

■ Some defined benefit schemes (that include final salary and career average pensions) can begin paying your pension early in the event of permanent ill-health. Usually, this type of pension is reduced if it's paid early, but many schemes won't make this reduction. The maximum amount payable is what you would have got if you continued working to your normal retirement date.

■ If you decide to use some or all your pension pot to purchase an annuity to provide a guaranteed income for life, an impaired life or enhanced annuity could give you a higher level of income. The annuity rate you're offered is based on an estimate of your personal life expectancy. This is calculated using the medical information supplied.

- It's not possible to receive your State Pension early, and the amount of money you get from any income-related benefits could be affected if you take your private or workplace pension early, such as:
  - Housing Benefit.
  - Income Support.
  - income-based Jobseeker's Allowance.
  - income-related Employment and Support Allowance.
  - Pension Credit.
  - Universal Credit.

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ILL-HEALTH EARLY RETIREMENT

If you do retire early because of ill-health, you may be entitled to other benefits. Use a benefits calculator to check.

- If you do retire early because of ill-health, you may be entitled to other benefits. Use a benefits calculator to check. If you want to know more about how taking early retirement can affect your benefits, you can get help from:

  - Citizens Advice: **https://www.citizensadvice.org.uk**
  - Money Helper: **http://tinyurl.com/yc4ykb8p**
  - Benefits calculator: **http://tinyurl.com/5n7xsfa4**

- **Pension Wise** can help to make sense of how and when you can access your private pension pot. It is a government service that offers free, impartial guidance over the phone. After your appointment, you might want to get advice from a regulated financial adviser for individual advice on the best way of turning your pension pot into your retirement income based on your circumstances:

  http://tinyurl.com/2k6u3kkx

- NHS workers and teachers in the UK can both claim their workplace pensions before retirement age due to ill-health, often without the usual reductions applied to other early retirement pensions. Both have their own rules, criteria and restrictions, so do some background reading or ask your employer for their policies. See also:

  Unbiased: NHS Pension advice:
  http://tinyurl.com/2ax5y2xf

  Unbiased: Teachers pension schemes: Everything you need to know:
  http://tinyurl.com/yzr8jejz

2. The process

- Most pension schemes have their own criteria as to what sort of conditions will entitle you to draw your pension early and how they define permanent ill-health or disability. You will almost certainly need to:

  - Establish that you are permanently incapable of continuing to do your current job – this can be due to a physical or mental condition – and will require supportive medical evidence that might include a medical assessment from the pension provider.

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ILL-HEALTH EARLY RETIREMENT

- Demonstrate that there are no treatments available that could enable a successful return to work before normal pension age. This could apply to a current role or any alternative employment. Pension schemes will also consider whether you are working full- or part-time and may suggest part-time working as a solution.
  - Apply while you are in pensionable employment for maximum benefits. This is not essential but is recommended.

■ Pension providers are now placing much greater emphasis on rehabilitation and reasonable adjustments (see above) to enable an employee to return to work. If an employer is genuinely able to facilitate a return to work, and you feel able to return, the application for early retirement will be less likely to succeed. However, if an employer offers a different role and/or fewer hours, you may still be able to apply for ill-health retirement because it differs from your current role and provides a reduced income.

- The criteria and procedure for each scheme will differ. Ask your pension provider exactly what they need from you. It's a good idea to enlist the support of an independent financial adviser (IFA). They can guide you through the process, ensuring you know your rights and complete each step accurately.
- Steps generally include:
  - Complete a copy of the ill health retirement application form from your pension scheme.
  - Get medical proof confirming your condition. This could be a letter or signature on the application form from your doctor. It could also require a more objective and independent professional assessment from medical advisers.
  - Get confirmation from your employer that ill-health is the only reason for your retirement.
- Once your application is submitted (either by you or someone on your behalf) your provider will either award the benefits, request more evidence, or reject your application.

Get medical proof confirming your condition. This could be a letter or signature on the application form from your doctor. It could also require a more objective and independent professional assessment from medical advisers.

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ILL-HEALTH EARLY RETIREMENT

- The scheme will need to provide detailed reasons for rejection, so that you can appeal if you don't agree with their reasoning. If you appeal, ensure you do so within the allocated timeframe and remember you may need to provide fresh medical evidence.

Source: Unbiased: Ill health early retirement: What are the qualification criteria?
http://tinyurl.com/ykzu7xwe

INCOME PROTECTION INSURANCE (IPI)

Income Protection Insurance (also known as Permanent Health Insurance) can pay you a regular income (and/or a lump sum) if you are unable to work because of sickness or disability. The income would normally continue until you are able to return to paid work or you retire.

■ Income Protection Insurance (also known as Permanent Health Insurance) can pay you a regular income (and/or a lump sum) if you are unable to work because of sickness or disability. The income would normally continue until you are able to return to paid work or you retire.

■ People with ME/CFS can experience a variety of problems when it comes to IPI claims. Not surprisingly, we receive anecdotal reports indicating that some companies are not sympathetic, or are even hostile, to claims relating to this illness.

■ Overall, we receive very little feedback about problems with the initial claim – in most cases this is accepted provided a firm diagnosis of ME/CFS or PVFS has been made and you are clearly unable to complete paid work.

■ Problems can arise once the claim has been going for a period of time – often as a result of a further medical or occupational health assessment – and you might be pressured into doing, regular exercise, for example. However, the National Institute for Health and Care Excellence published a new Guideline on ME/CFS in October 2021:

- This is a framework of evidence-based recommendations to the NHS and social care providers.
- Any insurance company or appointed medical representative should be familiar with the Guideline – and should bear in mind that Graded Exercise Therapy (GET), for example, is no longer considered appropriate.

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INCOME PROTECTION INSURANCE (IPI)

- The insurer might also come to the conclusion that you are now fit to return to work as a result of a subjective functional assessment, even though you and your doctor do not agree:
    - RWK Goodman solicitors has an expert team available (see below) for IPI claims relating to ME/CFS or Fibromyalgia, for example. They advise that:
        - if during the period when your claim is being reviewed you are asked to attend an assessment, you seek advice beforehand, take someone with you, and avoid any home assessment unless absolutely necessary.
        - the GMC Good Practice Guidelines (2013), state that the doctor should have expertise in the condition and should not leave out any relevant material.
        - you take great care and always attach a more detailed schedule to any Activity Questionnaire you receive as they are normally space limited.
        - insurers actively use surveillance and monitor social media.

Visit Medical Matters on the ME Association website to find out more about what to consider with regard to PHI.

More information

Medical Matters on the ME Association website: Income Protection Insurance (IHI).
http://tinyurl.com/2nz968tr

Citizens Advice: Income Protection Insurance.
http://tinyurl.com/dxrwrh4u

RWK Goodman solicitors: Denied PHI Guide.
http://tinyurl.com/tzsrfjmw

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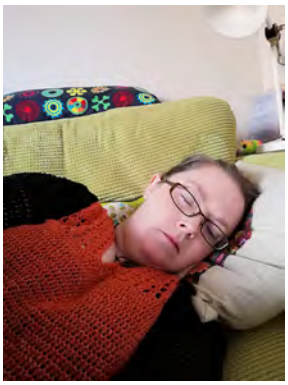
TERMINATION OF EMPLOYMENT



If a disabled employee cannot do their job because there are no reasonable adjustments that can be made, it may be fair for you to dismiss them.

■ The Government has established some guidance for employers on the subject of Dismissal that is just as relevant to employees and worth considering in the context of this booklet.

■ If you believe you have been unfairly dismissed, then you should take immediate action and seek legal advice.

■ We have taken extracts from the Government advice below.

1. Dismissal

- Dismissal is when you end an employee's contract. When dismissing staff, you must do it fairly.
- There are different types of dismissal:
  - fair dismissal.
  - unfair dismissal.
  - constructive dismissal.
  - wrongful dismissal.

2. Disability

- If a disabled employee cannot do their job because there are no reasonable adjustments (see above) that can be made, it may be fair for you to dismiss them.

3. Dismissals due to illness

- Sometimes an employee may have to stop working because of long-term ill health. They may resign, or you may have to consider dismissing them.
- Dismissal is a last resort, and you should consider as many ways as possible to help the employee back to work, including:
  - getting a medical report from their GP with the employee's permission - they have the right to see the report before you do.
  - arranging an occupational health assessment.

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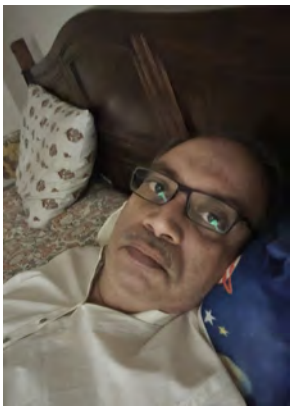

TERMINATION OF EMPLOYMENT

- work out whether or not they are classed as disabled under the Equality Act 2010 and make any reasonable adjustments to help them do their job.

- If the employee cannot do their job because there are no reasonable adjustments that can be made, it may be fair for you to dismiss them, even if they're disabled.

4. How to dismiss someone

- During the dismissal procedure, make sure you act fairly and reasonably. You must treat the employee with sensitivity.

- In England, Scotland, and Wales, follow the advice set in the Acas (Advisory, Conciliation and Arbitration Service) Code of Practice.

http://tinyurl.com/fr8uuaub

- In Northern Ireland, follow the advice set in the Labour Relations Agency (LRA) Code of Practice.

http://tinyurl.com/2mxtdv8u

Source: Gov. UK: Dismissing Staff.
https://www.gov.uk/dismiss-staff

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COMMUNITY COMMENTS

If you work, do you manage to work part-time or full-time? How does your employer support you? What kind of work are you able to do with ME/CFS?

3

"I'm working part-time now, and only manage that because my boss allows me to be incredibly flexible with my hours. I had to give up my ambition of working with horses towards the end of my equine degree, and then I had to give up my career in teaching because of ME/CFS. I'm only now looking at applying for benefits because Covid-19 has exacerbated my symptoms. But as I've been waiting about 2 months for the application forms to arrive, I'm not expecting it to be a straight-forward process!"

1) "A few years ago, I found myself in a position where my employer made changes to the pay and reward system that disproportionately affected people with disabilities.

"I had a flare up of ME/CFS during the reporting period and was not adequately supported by management nor did they properly account for the difficulties I faced because of my condition when assessing me under that system. With the support of my union, I managed to appeal my specific outcome, and have it overturned.

"The union then chose to progress the case to employment tribunal on my behalf, as well as several other employees who were similarly affected. In the end it was settled in mediation, but we were all awarded additional compensation.

"It was an incredibly stressful period which I would have preferred to never have faced, but ultimately the outcome was successful, and it helped with my confidence that it was formally acknowledged that I was treated unfairly."

2) "I am now retired. When I first succumbed to ME/CFS, I was a full-time teacher, but then over a 5-year period I had 4, 6 and 8 months off work because of my disability. I worked full-time between each episode, and I was able to continue working until I took early retirement in 2008. Since then, I have had a 2-year episode and am at present in another episode which so far has lasted 4 years. In was able to stay in my position due to excellent conditions of service. I was able to teach in each case until the symptoms got too bad, but I didn't have a social life."

4) "I was in a cycle of working and burning out for about 10 years prior to diagnosis. But I've managed to work full-time for the last 2 years being very careful to manage my energy.

"My employer has been good overall, especially my manager. The Access to Work Assessment helped my employer provide things like leg-rests and noise cancelling headphones.

"It took my employer a long time to accept the recommendations, but it was worth the wait. If it wasn't for the support from my manager I'd have been tempted to give up.

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COMMUNITY COMMENTS

5
"I have been working from home since the start of the pandemic but used to have to go and sleep in my car most days when I was at work. I'm dreading going back to the office because I don't know how I will feel, and I'm scared I won't be able to cope."

"Working from home during the pandemic has been a godsend. I'm lucky because I feel that ME/CFS is in remission most of the time, but even so, it's still a challenge to keep working and I took a few days off last week because I wasn't well."

6) "Best decision I made was to go part-time very early on in my diagnosis. It was financially challenging and one of the hardest decisions I had to make, but the alternative would have led to no work. I'm fortunate to be at a place in my career where I'm in an advisory role and have largely worked from home since March 2020 - the Covid pandemic was useful for that. Been tempted to increase my hours, but I know a return to the office would make that more difficult. Homeworking is providing a false picture of my health, but it has helped so much."

7) "I'm now self-employed so I can better manage my workload. I was a college lecturer and co-coordinator when I got ME/CFS and off sick for a year before being "paid off". I lost a career I was passionate about, but I have survived!"

8) "When I was first diagnosed, I was bullied and ended up leaving my place of work due to stress. Three years later and I'm in a much better environment. I'm lucky that my new role as head of marketing has allowed me to work from home when needed, is flexible and my employer is very understanding of the condition. I think it's about understanding and education. Long-term health conditions suggest the employee will always be off sick, when the reality is with the right support and adjustments, people with mild/moderate conditions can find suitable employers and roles. But I still struggle and too much work does take it out of me."

9) "I had to leave my job as my mental and physical health were deteriorating and I was having breakdowns at work. Unfortunately, I have a few invisible disabilities and I hate to think what the future has in store."

10) "I manage to work 4 days a week and because of the pandemic this is currently from home and will continue to be from home after the pandemic ends. My job is quite flexible so I'm able to start around 10.30am and can take breaks as needed. I spend my day off doing nothing so I can have some energy to do something at the weekends. In the past I have had to take several months off sick due to relapses, but my company has been very accommodating, I'm very fortunate. Also, I'm in a more senior role than I was when I started at the company 13 years ago (have had ME/CFS 21 years). Obviously, it's still not easy but I know I'm more fortunate than most in this situation."

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COMMUNITY COMMENTS

11

"I worked part-time for years with two 9-month absences because of ME/CFS. For the past year or so, I've managed to work full-time. Not out of choice but necessity. I'm exhausted all the time. I sleep/rest after work and Saturday's often mean several naps. My annual leave invariably means I crash and then try to recover. These arrangements are not ideal and certainly impact my health, but I must prioritise providing for my family and ensuring my mortgage etc. is paid each month."

12) "I work as a Teaching Assistant. My school has been very accommodating. It works well for me as the pace and variety means that I don't do anything for too long – a little walking, a little sitting and listening, a little thinking, speaking, writing etc. I have rest-breaks every 2 hours and I take regular holidays. I was full-time but after 3 years during which I was off work sick quite a lot, I have reduced work to 3 days a week – every other day.

"I negotiated 'reasonable adjustments' to ensure that the work I do doesn't take me beyond my abilities. I have had to be very firm about the conditions and I documented everything. I still have weeks off sick at times but have yet to reach absence trigger points. I am considering adding a clause to the adjustment's agreement regarding ME/CFS sickness absence. I greatly value being able to work and having a purpose. It takes me out of myself. I enjoy working with my colleagues and have made sure they understand the effects this disease has on me."

13) "I manage to work two 7-hour days, but they really take it out of me, and I struggle for the rest of the week. My employer is understanding. I told them all about my disability at the initial interview as I wanted to be completely upfront from the start.

"I work in the third sector for a small charity in Yorkshire. I was previously a full-time community development worker, but that employer was not understanding. I reduced my hours gradually but still found the work too demanding, so I looked for a position with less responsibility. This has meant less pay, so financially it's extremely hard, but I'm lucky to be supported by my partner."

14) "I work for the NHS and reduced work to 3 days a week around the time my ME/CFS started in 2016. I survived on a boom-bust-cycle until I deteriorated. I renegotiated my working hours and did 2 short days on site and the rest from home. My manager and colleagues have been extremely supportive. I managed well through pandemic probably because apart from working I was doing little else! I think I finally found my activity baseline. Unfortunately, I deteriorated again in February and have been off work sick since. Been doing all the right things as far as I know but have seen no improvement. My work future is looking very uncertain."

16) "I went from 5 days a week higher level teaching assistant in a school to having to leave, recover and start a new job as a receptionist. The job I left was not necessarily as supportive as they should have been, but my new employer has been great, especially since I had a crash about 8

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COMMUNITY COMMENTS

15

"I have been off work now for nearly 6 months, with no improvement. I have had to make the hard decision to reduce my responsibilities and cut my hours in order to attempt a return but I'm going to really struggle financially. The thought of going back to work is making me anxious."

weeks ago. They were fully supportive of a phased return. I may have to reduce the hours again, but we'll see."

17) "I became ill with ME/CFS while working full-time. After a period off work, I went back part-time. The company didn't like this arrangement and forced me out because of my disability. Following this my health declined. I haven't been able to get back to work since."

18) "I went from a full-on full-time job in a management role to building up to 2 days a week doing data entry for a small charity. Sadly, ME/CFS robbed me of the chance to raise a family, so we decided to limit any work pressures but it's a real battle to find roles that fit."

19) "I dropped out of university due to ME/CFS 15 years ago. I managed to work full time but spent all my evenings and weekends in recovery. I persevered until a large crash 5 years ago and took a couple of months off sick. I started back on a phased return, but I've never quite got back to full-time. I dropped my hours and start work 30 minutes later and finish an hour later. I am doing 30 hours a week. It takes a lot out of me, but I can't afford to go part-time as I don't think I'd get any help from the government. I spend most evenings and weekends recovering and don't go out socially."

20) "Sadly, I was treated very badly by my employer. I was made worse during a phased return. Forced to take legal action even though I was sick. I won."

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"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."

HOW WE CAN HELP

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today**.

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. We have knowledge and understanding of these medical conditions. To view the ME Connect telephone helpline opening hours please visit: **https://www.meassociation.org.uk/me-connect**

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of free literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations of the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

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"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."

HOW WE CAN HELP

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guideline reproduced in full in an easy-to-use **database**.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy-to-use **database**.

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THE ME ASSOCIATION

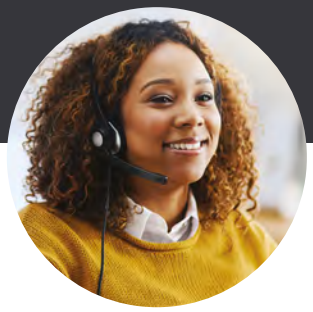
ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email or social media private message

Freephone 0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!

meconnect@meassociation.org.uk

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facebook.com/meassociation

instagram.com/meassociation