



**Employment and Support Allowance
and Universal Credit claims on
the grounds of ill health**

**The ME Association Guide
to filling in the forms**

January 2020

Contents

Introduction	3
Part 1: Types of ESA - New Style	3
Types of ESA – Contribution-based	6
Types of ESA – Income-related	7
Relevant Supporting Information	9
Part 2: Work Capability Assessment Questionnaire	13
Part 3: The Face-to-Face Assessment	33
Final Words	35

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The ME Association is indebted to our Welfare Rights Adviser, Ann Innes, for the text of this Guide. Ann has been helping people with ME/CFS claim the benefits they are entitled to since 2012 – when she was employed by the Stockport ME Group. She has her own private practice helping disabled people access benefits, social care support, appropriate housing and other services.



The ME Association welcomes feedback about this guide.

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Benefit payment rates in this guide all relate to financial year 2019-20

INTRODUCTION

This three-part guide is intended for those making both new claims for ESA or for Universal Credit based on health grounds. People making a renewal claim will also find it helpful.

The rules governing benefits are complex and ever-changing. This guide does not pretend to provide a full list of all them. It's a general overview only. It is always sensible to seek detailed advice from a welfare rights specialist.

There are three types of ESA: New Style ESA, contribution-based ESA and income-related ESA. In order to claim any of these, you must be of working age (aged 16 or over but under state pension age) and have an illness or impairment that affects your ability to work.

Part 1 highlights some of the main differences between the three types. It also supplies helpful information on making a new claim for ESA or for those claimin Universal Credit and undergoing their first "Work Capability Assessment". It gives an insight into the assessment process and how to submit relevant supporting evidence. Finally, it touches upon what to do if you are not happy with the decision.

Part 2 is intended to be used as a guide to complete the UC50 or ESA50 Work Capability Questionnaire.

Part 3 tells you what to expect at a face-to-face assessment.

Part 1: Types of ESA

NEW STYLE ESA

Who can claim?

Generally speaking, New Style ESA has replaced new claims for contribution-based Employment and Support Allowance.

In order to claim, you must be of working age (aged 16 or over but under state pension age) and have an illness or impairment that affects your ability to work.

You must have paid enough UK National Insurance in the two tax years before the date you are claiming (or the equivalent in another country with which the UK has an agreement). You can check whether you have paid enough National Insurance by following this link:

<https://www.gov.uk/check-national-insurance-record>

If you haven't paid enough National Insurance, you may be able to claim Universal Credit instead if you (and your partner if you have one) are on a low income with savings below £16,000.

See our Universal Credit leaflet for further information on how to claim Universal Credit:

<https://www.meassociation.org.uk/shop/benefits-leaflets/universal-credit-explained/>

To be able to claim, you must live in Great Britain. But you can also claim for the first 26 weeks of a temporary absence if that absence is "solely in connection with arrangements made for treatment for a condition directly related to your limited capability for work, which began before you left Great Britain; or

because you are accompanying a dependent child in connection with arrangements made for treatment of their condition” by an “appropriately qualified” person. You can also leave Great Britain for up to four weeks and still be eligible for ESA.

You can also continue to claim ESA for the first four weeks of a temporary absence from Great Britain if the period of absence is unlikely to exceed 52 weeks and if you continue to meet the other qualifying conditions for the benefit. Let the Department for Work and Pensions (DWP) know if you are going abroad.

The residence rules change if you live in another European Economic Area (EEA) country – where you can continue to receive New Style ESA or contribution-based ESA.

You must also have been found to have either limited capability for work or limited capability for work-related activity. This is established through the Work Capability Assessment.

You must not be in a period of entitlement to Statutory Sick Pay or Statutory Maternity Pay. You won't qualify for a wide range of other benefits at the same time as you receive ESA. If you are entitled to another benefit, you would need claim it. But you'll only be paid whichever is the higher.

You mustn't be working either, unless it is what is called 'Permitted Work' – less than 16 hours a week and for which you receive no more than £131.50. Complete form PW1 to ask the DWP's permission. You should also tell them about any voluntary work you do or plan to do.

Your savings, capital and any other income should not be taken into account for New Style or contribution-based ESA but any occupational or personal pension may be taken into account so they should be declared. You must also notify the DWP every April, when your pension is increased. The exception is if you have been claiming Incapacity Benefit or Severe Disablement Allowance since 2001 before you were moved over to ESA.

If you are on a low income with savings below £16,000, you may also be eligible to claim Universal Credit. It is often advisable to do so as you can only claim New Style ESA for 365 days unless you have been assessed as having “limited capability for work-related activity”. If you are awarded both benefits, the amount of New Style ESA will be deducted from your Universal Credit.

Special rules

If you are suffering from a progressive disease and expected to die within six months, you can claim under Special Rules. Your claim will be fast-tracked and if a GP, consultant or specialist nurse can confirm that you are terminally ill (a DS1500 form is the quickest way for them to do this), you will be automatically assessed as having both limited capability for work-related activity and limited capability for work – as long as you meet the other criteria listed above.

How to Claim New Style ESA

Fill in the form NSESAF1 online or download, print off and complete a paper copy by following this link:

<https://www.gov.uk/government/publications/new-style-employment-and-support-allowance-esa-claim-form>

If you complete the form online or download and print the form off for posting back, you will need to make a “New Claim Appointment” straight away by calling 0800 328 5644 (option 2, followed by option 6) or by Textphone on 0800 328 1344.

These numbers can also be used to request a form be posted out to you. If you request a form in this way, you should be contacted within a week to book a New Claim Appointment. If you haven't heard anything after a week, the Department for Work and Pensions (DWP) request that you chase them up on the phone.

If you prefer to obtain the form in person from your local Jobcentre Plus, you will be made an appointment when you collect the form.

If your SSP is running out, make a claim up to three months in advance to minimise delays.

Completing form NSESAF1

This initial claim form is not the work capability assessment questionnaire (ESA50) that asks for details about how your illnesses and / or impairments affect you. Rather it asks specific questions around income.

However, if you still need help to complete the form, this may be available from organisations such as Citizens Advice, a local law centre, a local statutory welfare rights advice service or a disability rights or impairment-specific charity.

When completing your claim, you can ask for your claim to be backdated for up to three months, as long as you have a fit note to cover that period and met the eligibility criteria detailed above during that time.

The New Claim Appointment

At your "new claim appointment", you will need to supply a fit note from your GP if you've been absent from work for more than seven days.

If you are still employed but your Statutory Sick Pay is ending, you will also need to provide form SSP1 to the DWP, which you can get from your employer. You will also need to take your completed claim form for checking, together with your ID, proof of address, proof of any pensions or health insurance and any other supporting evidence.

During your appointment, you will talk with the adviser about any help and support you might need to get back to work. If your condition is such that any work-related activity could cause a setback in your condition, it would be helpful if any supporting evidence you supply from your health professionals states this.

After four weeks you will be asked to attend a mandatory "Health and Work Conversation" with a work coach at your local Jobcentre Plus, to find out what support is needed to move you into work. Some people don't have to attend this conversation. Follow this link to find out whether you are exempt:

<https://www.whatdotheyknow.com/request/404506/response/985786/attach/4/HWCExemptions.pdf>.

If you are exempt and asked to undertake any work-related activity, it would be sensible to take medical evidence with you to your first appointment or to write to the DWP stating you believe you are exempt and backing this up with medical evidence.

Even if not exempt, you may be able to request that any future work-focused activity or work-related activity is deferred as a reasonable adjustment under the Equality Act 2010 until after you have undergone the Work Capability Assessment.

Again, make this request as soon as possible, either in writing or in person. You stand a better chance

if this is backed up with medical evidence from one of your healthcare professionals stating that work-focused activity would cause a deterioration in your condition or a worsening of your prognosis.

If you are too ill to attend an appointment at Jobcentre Plus, inform the DWP on the number above that you require a home visit. It will be necessary to supply supporting evidence from a health professional such as your GP, consultant or M.E. nurse, if you have one, explaining why your condition(s) would stop you attending an appointment – if you are housebound, for example, or if attending an appointment would cause your condition to worsen.

CONTRIBUTION-BASED ESA

New claims

Generally speaking, New Style ESA has replaced Contribution-based ESA for new claims.

However, people entitled to a Severe Disability Premium with an existing means-tested benefit (eg housing benefit), or who were entitled to Severe Disability Premium within the last month of making a new claim can make a new claim for contribution-based ESA. If you (and your partner if you have one) are on a low income with savings and /or capital under £16,000, you may also be able to claim income-related ESA at the same time as a top-up to your contribution-based amount.

Eligibility Criteria

Contribution-based ESA has the same eligibility criteria as New Style ESA, detailed above (*see pages 3-4*).

How to claim

Applications can be made Monday to Friday between 8am to 6pm by telephoning 0800 169 0350, via textphone on 0800 023 4888, via NGT text relay on 18001 then 0800 169 0350 or Welsh language telephone on 0800 012 1888.

Alternatively, download the ESA1 form by following this link:

<https://www.gov.uk/government/publications/employment-and-support-allowance-claim-form>

and take or send the completed form to your nearest Jobcentre Plus which can be found by following this link:

<https://find-your-nearest-jobcentre.dwp.gov.uk/>

If you cannot use a computer, contact Jobcentre Plus to find your nearest office by telephoning from Monday to Friday 8am-6pm on 0800 055 6688, textphone on 0800 023 4888, NGT text relay (if you cannot hear or speak on the phone) on 18001 then 0800 055 6688 or the Welsh language phonenumber on 0800 012 1888.

If you are in Northern Ireland, you will need to call 0800 085 6318 or textphone on 0800 328 3419. You can also download a claim form here

[https://www.nidirect.gov.uk/sites/default/files/publications/EmploymentandSupportAllowance claimformESA113.01.17.pdf](https://www.nidirect.gov.uk/sites/default/files/publications/EmploymentandSupportAllowance%20claimformESA113.01.17.pdf)

and post it to:

Employment and Support Allowance Centre, Mail Opening Unit, PO Box 42, Limavady, BT49 4AN.

You can request forms in accessible formats, such as large print, audio CD or Braille.

Existing claims

Existing claims will continue as long as you continue to meet the eligibility criteria for the benefit. There are no plans to move people on contribution-based ESA to New Style ESA as they are essentially the same benefit.

If you are unsure whether you are on contribution-based ESA or income-related ESA, the calculation page of your award letter should tell you. If it is still unclear, contact the DWP to check by phoning the number on the top of your award letter.

INCOME-RELATED ESA

New claims

Generally speaking, Universal Credit has replaced Income-related ESA for new claims.

See our leaflet on Universal Credit for more information:

<https://www.meassociation.org.uk/shop/benefits-leaflets/universal-credit-explained/>

However, if you get or are entitled to a Severe Disability Premium with an existing means-tested benefit (eg housing benefit), or were entitled to Severe Disability Premium within the last month of making a new claim, you can still make a new claim for Income-related ESA. If you have enough National Insurance credits, you may also be entitled to contribution-based ESA. The DWP will assess this when you make your claim.

The person claiming must be of working age and under state pension age and be found to have limited capability for work or work-related activity.

You (and your partner if you have one) must be on a low income and have savings and/ or capital that does not exceed £16,000 to claim.

Your partner must not be engaged in paid work for 24 hours or more a week (or be treated as such), nor be entitled to income-related ESA, income-based JSA, Income Support or Pension Credit in their own right. If they are entitled to income-related ESA in their own right, it would be sensible to seek advice on which one of you should claim.

You must not be subject to immigration control, must have the right to reside and meet the habitual residency test.

You must not be in education (unless you receive DLA, PIP or Armed Forces Independence Payment).

How to Claim

Income-related ESA can be claimed in the same way as contribution-based ESA detailed in the previous section. (See page 6).

Existing Claims

If you are currently on income-related ESA and your circumstances remain the same, you will remain on ESA until you are moved over to Universal Credit. This could happen any time between now and 2023.

If you have a change of circumstances in an existing ESA claim that means you will need to make a new claim for any means-tested benefit (such as moving to a different local authority and requesting help with paying your rent), you will be asked to claim Universal Credit straight away, – unless you are already receive Severe Disability Premium or were entitled to it in the month before to your claim.

The Assessment Phase (this applies to both Universal Credit, if claiming because of your health condition, and to ESA)

How much will I get?

During the first 13 weeks of your claim, you will be paid a basic allowance of either £57.90 if you are under 25 or £73.10 if you are over 25 and under state pension age, until a decision has been made on whether you have limited capability for work or limited capability for work-related activity.

Payments are made fortnightly into an account of your choice. In certain circumstances such as terminal illness or if your claim links to a previous ESA claim, you may be eligible to be paid at the main phase rate so, if you think this might apply to you, please seek professional advice.

Your payments should be backdated to the date on which you make your claim – or in the case of contribution-based ESA or New Style ESA up to three months before this date as long as you have a fit note to cover you for that period and met the eligibility criteria, You will have to request this backdating when you claim.

During this time you will be required to provide regular fit notes. Failure to keep up-to-date with this will lead to your payments being suspended.

If your assessment is delayed and you continue to be paid at the basic rate after the first 13 weeks, the extra money you would have been entitled to should be backdated to the 14th week.

THE WORK CAPABILITY ASSESSMENT

The purpose of this is to assess whether your functional capacity is limited enough to meet the DWP's threshold of what constitutes either "limited capability for work" or "limited capability for work-related activity".

This is carried out by a healthcare provider contracted by the DWP. This is a firm called Maximus, who work under the name of "Centre for Health and Disability Assessments (CHDA)".

There are usually three stages to the assessment process.

1. The Work Capability Questionnaire

Everyone making a claim has to complete a questionnaire about how their illness or impairment affects them.

If you are claiming both Universal Credit and New Style ESA, you should only have to complete one medical questionnaire (ie either a UC50 or ESA50) but we know people who have been asked to

complete both. If this happens, contact the assessment provider who sent the form (the number should be on the accompanying letter) and explain the situation as they are only allowed to keep one live claim on the system.

The questions that are numbered on the claim forms correspond to “descriptors” – ie tasks that the DWP have decided give evidence as to your ability to undertake either work or work-related activity. Each descriptor has various points that someone can score for it, depending on their level of functional impairment.

Part 2 of this guide tells you about the point-scoring system and how best to complete the forms.

Send the questionnaire back on time – to ensure it is received by the given deadline. Take a photocopy of what you have written and return the form “special delivery” to get there either by the deadline if it is a weekday or by the Friday ahead of the deadline if your it falls on a weekend.

Unlike PIP claims, you cannot phone up and ask for an extension. You will be told to write your reasons on the form if you are returning the form late and you should back this up with medical evidence if the reason is M.E.-related. It will then be considered by a decision-maker.

However, there are no guarantees that a late submission will be accepted, so you should return your form on time. If it is a renewal claim you risk having your benefit stopped if you return the form late. If it is your first claim, you may have to start the process again from scratch.

RELEVANT SUPPORTING INFORMATION

■ The DWP state on the claim form not to ask or pay for new information but you may want to exercise your own judgment here. We are aware of cases where, because the medical evidence has been paid for, it has been given less weight. However, this is rare.

■ If you are going to provide medical evidence with your claim, it could make the difference between having to go for a face-to-face assessment or being assessed on paper. However, the evidence submitted needs to be relevant to the descriptors being assessed and not be a general letter stating diagnoses.

■ Our welfare rights adviser asks all her clients claiming ESA/UC to request that all their healthcare professionals complete the following form:

<https://www.meassociation.org.uk/wp-content/uploads/Guidance-notes-UC-claim-use-this.pdf>

This could be a GP, consultant, M.E. nurse, physiotherapist, counsellor or occupational therapist. You could also supply evidence from a social worker, personal pssistant /carer or a close friend or relative that acts as such.

■ Explain in detail to whoever you ask the difficulties you have with carrying out each descriptor. If you are asking your GP, you might want to book a double appointment. If you do not have the energy for a double appointment,, you could leave them a copy of your completed ESA form. However, this is not ideal. Remember that many healthcare professionals will offer telephone appointments if they will not grant you home visits, so this could be another option for you to consider.

■ If your healthcare professional would rather write a general letter, it would be helpful if they could use the form as a guide. Ask them to complete it and return it to you, not the DWP, as they may put something inaccurate on the form. Don't be afraid to ask them to change something in a letter or a form if it is in-accurate.

■ Some healthcare professionals will charge for this, some will want to correspond directly with the DWP, but at least, if you have provided them with information about your difficulties with the different

descriptors, you have a better chance of them completing the form accurately.

- We suggest asking other professionals involved in your health or social care, such as a consultant, M.E. nurse, physio, OT, social worker or carer/support worker or personal assistant if they would be happy to complete a standard form as well. An NHS consultant's letter carries the most weight, but that it is still useful to include supporting letters from private professionals, friends, family or carers to paint a picture.

- It is usually easier to give them a copy of your completed claim form before they write something, so that they make their evidence as relevant and accurate as possible (without copying the claim form word for word!).

- These supporting letters can always be sent in after you have submitted your claim, with a covering letter and your name and National Insurance number on the top of every page. So don't feel like you have to get the evidence straight away before you've even considered how you are able to carry out each descriptor.

- If you have a care package from Adult Social Care, you should have a copy of your care assessment. As long as this is accurate, it can also be a useful piece of evidence to submit.

- When submitting supporting evidence, never submit the originals. Send a photocopy and ensure that your name, national insurance number and the letters "FME" (further medical evidence) are on the top of very single page – if you are sending something double-sided, ensure that this information is on both sides.

2. The Face-to-Face Assessment

Once the healthcare provider receives the questionnaire, it is handed to the medical assessment team, who decide whether a face-to-face assessment is necessary.

If you do have to attend an appointment, as soon as you receive your appointment letter contact the number on the letter straight away and request a recording of the assessment, even if you have already made a request to record on your claim form. Remember to take the name of the person you spoke to, the date and time of the call and either the contact centre they are in / their extension number / their ID number.

Try not to attend the appointment on your own. If you need to change the appointment to a time where you can be accompanied by someone, remember you are only allowed to change your appointment once. So ensure you carefully check the availability of the person who you want to attend with you before changing your appointment.

Part 3 of this guide will explain more about the face-to-face assessment.

3. The Decision

Once you have been assessed, the healthcare provider will return your case file to the DWP where it will be given to a "decision-maker", who will make a decision based on the healthcare professional's assessment report.

They should also take into account any supporting evidence you have sent in. But, in reality, the decision is usually solely based on the assessment provider's report. The decision-maker will then decide whether you have limited capability for work or limited capability for work-related activity. The distinction is an important one.

With a New Style ESA claim, if you are assessed as having limited capability for work you will be placed in the “work-related activity” group and you can only claim for 365 days in this group with a New Style ESA claim (the same is true of a contribution-based ESA claim). However, you can still ask to continue to be assessed after 365 days in order to continue to receive National Insurance contributions towards your pension and it would generally be advisable to do so.

If you are assessed as having “limited capability for work-related activity” you will be put in the Support Group and, as long as you continue to meet the eligibility criteria, your claim will not be limited to 365 days.

With a Universal Credit claim, instead of being put in one of these two groups, you will receive either the “limited capability for work” element or you will receive the “limited capability for work-related activity” element.

Whether New Style ESA or a UC claim, if you are assessed as having “limited capability for work-related activity”, you shouldn’t be subject to any “work-related” requirements and should effectively be left alone until you are reassessed. You will receive an extra £38.55 a week on top of your basic rate.

If you are found to have “limited capability for work” you will continue to receive only the basic rate and may be subjected to the benefits cap – a maximum threshold per household of how much benefits one household can claim.

You will also be required to undertake regular work-related activity of a nature and at times specified by your work coach from Jobcentre Plus or a work-related activity provider.

With a fluctuating condition such as M.E., such a requirement can prove difficult if not impossible for many people, but failure to attend can result in a sanction, whereby your benefit can be drastically reduced if you cannot show “good cause”. Good cause relating to your health condition needs to be backed up with specific medical evidence stating that your condition prevented you from being able to take part in said work-related activity.

The DWP will write to you with their decision. Once their decision has been made, if you are deemed to be eligible, you will be in what is called “main phase”. The decision letter should tell you that you no longer have to supply fit notes, detail which component / element you have been assessed as being eligible for and give a breakdown of the money you will receive.

You have one calendar month from the date on the decision letter to ask for them to look at their decision again if you disagree with which group you have been placed in or if you have been told you are not eligible for any benefit. This is called a Mandatory Reconsideration request.

If you are disputing the group you have been placed in, the decision is then usually passed to another decision-maker (although we have had cases where it has been passed back to the same decision-maker) to be looked at again.

They will look at the whole decision again, not just the parts you disagree with, so bear in mind that you are risking what you have already been awarded being taken away. If you are in this situation, ask for independent advice from Citizens Advice or your local Welfare Rights Service to see whether your case is strong enough to risk asking for a Mandatory Reconsideration.

Put your request for Mandatory Reconsideration in writing and explain which descriptors you feel you should have scored on, why and also supply medical evidence to back this up. You won’t receive any money whilst you are going through the Mandatory Reconsideration stage.

If your Mandatory Reconsideration is unsuccessful and you decide to lodge an appeal, you can do so using form SSCS1, available here:

<https://www.gov.uk/government/publications/appeal-a-social-security-benefits-decision-form-sscs1>

or contact your local Welfare Rights or Citizens Advice office. If you cannot access an online version or collect one from the Citizens Advice, the Courts and Tribunals Service (HMCTS) can send one out to you, although you will be encouraged by them to access the online version or to collect a paper version if at all possible. They can be reached on 0300 123 1142 if you live in England or Wales, or 0300 790 6234 if you live in Scotland.

You have one calendar month from the date on the Mandatory Reconsideration notice to submit your appeal.. At this point, your ESA should be reinstated at the basic rate while you are awaiting your appeal hearing.

Again it is advisable to seek advice and help in doing so, as an appeal can be a daunting process and you could risk losing your existing award, if you were given one. Bear in mind, in the first three months of 2019, the average waiting time for an appeal to be heard was 30 weeks but this means it could be longer.

For further information on Mandatory Reconsiderations and Appeals, see the MEA's guide:

<https://www.meassociation.org.uk/shop/benefits-leaflets/mea-guide-to-esa-and-pip-reconsiderations-and-appeals>

Reassessment

You could be reassessed any time between six months and three years.

The DWP has said that those with the most serious health conditions which are unlikely to improve should not be reassessed. If you can get medical evidence to state this is the case for you, that could be helpful. You might want to refer to the independent CFS/ME Working Group's 2002 report to the Chief Medical Officer, which states on page 7 that, after five years, the prognosis is not favourable:

<https://www.meassociation.org.uk/wp-content/uploads/CMO-Report-2002.pdf>

Golden rules when contacting the DWP or any of their providers

Always remember, whenever contacting the DWP, to record the name of the person you spoke to, the contact centre and department they are in and the date and time of the call.

If you are sending any forms or medical evidence to the DWP, please remember to keep a copy. It is advisable to send via either "special delivery" if there is a deadline, or via "signed for" if not and use Royal Mail's tracking service to check that whatever you have sent has been received. Print off or make a note of the date and time received and the name of the person who signed for it.

Part 2: The Work Capability Assessment Questionnaire

The ESA50 / UC50 Questionnaire allows the DWP to score you on a variety of different physical and cognitive tasks to assess your degree of functional impairment and how it affects your ability to work or undertake work-related activity with a view to moving towards work. These tasks are called descriptors.

Each descriptor has a variety of scores, depending on your level of difficulty carrying out that descriptor. In order to pass the Work Capability Assessment at all, you must score at least 15 points across all the descriptors.

To qualify for the “limited capability for work related activity” you must score a full 15 points on any of the “limited capability for work related activity” descriptors, which we will list below.

General Advice on Completing the Questionnaire

■ Get help to complete the ESA50 / UC50 as this plays an important role in the assessment process. People often answer incorrectly unless they are aware of the assessment criteria, which this guide aims to shed some light on.

■ When completing the form, think about the questions in the context of a work setting – working 16 hours or more a week. Remember, the DWP are assessing your ability to carry out any type of work, not just your previous job. In such a context, you would be expected to carry out each descriptor **regularly, reliably, repeatedly and safely, within a reasonable timescale, without significant discomfort and to an acceptable standard**. It must also apply for either most of the time, or the majority of the occasions that someone attempts that descriptor.

■ **Do not complete the form as though it is your worst day.** Yes, you do need to focus on what you can't do rather than what you can do, but explain the variability. The reason I say this is that I have seen clients over the years omit to talk about variability, so that when they either are at their face-to-face assessment or in front of a tribunal panel, they seem “fine” – they can communicate, walk to the assessment room, handle their papers, etc – yet when someone looks at the form it sounds as though they are permanently bedridden and can never communicate. The first thing someone assessing you will think is that you are not credible, or that you have exaggerated your condition.

■ If you can carry out a descriptor once or twice but could not do so repeatedly and at will whenever you would like, you need to make this clear. You also need to make the level of frequency you could carry something out clear. If you are unclear as to how often you can do something because your condition fluctuates so much, think in terms of whether it is more often than not that you can do something or less often than not. If it is less often than not, make that clear in your answers.

■ If your condition fluctuates throughout the day, again make this clear – for example, you might answer,

There are times throughout the day more days than not / every day where I would be unable to repeatedly carry out this descriptor due to {list your symptoms here} caused by the M.E.

■ If your M.E. fluctuates throughout the week but is stable throughout the day, you might write,

I have bad days and better days but for more days than not I would be unable to carry out this descriptor because of {list your symptoms here} caused by the M.E.”

Be specific about what symptoms and which corresponding condition creates difficulties with the descriptor in question.

- If you have good weeks and bad weeks, explain this, but qualify by using “more often than not” or “less often than not” to explain variability, or “for over half the time”. With variability you should be assessed on how you are for 51% or more of the time.
- If the task described in a descriptor takes you a long time, for example because you need to keep stopping and taking rests, explain how long and why. If you can’t perform a task to an acceptable standard, again, explain why.
- Make sure if you can carry out a descriptor that you clarify the after-effects of doing so. Post-exertional malaise is one of the hallmark symptoms of M.E. and, if carrying out a descriptor triggers this symptom for you, explain this on the form.
- Don’t expect that whoever is looking at your form will understand phrases such as “pacing”, “post-exertional malaise”, etc. They may well know nothing about M.E. – it is up to you to be very clear on your form about what symptoms you experience when experiencing post-exertional malaise.
- **Repetition is key.** Don’t assume by the third descriptor that you don’t need to explain all of the above because you have done so earlier in the form.
- You can write outside the boxes and you can also attach additional sheets. But remember this can go against people. They have written so much additional information that it looks like they have excellent cognition as they have virtually written an essay! If it has taken you a long time to complete the form, make it clear that you have had to do it in stages in the “other information” section. Also make it clear here if you have had help to complete the form.
- If you are attaching additional sheets, remember to write your name and National Insurance number on the top of every sheet and again keep copies of what you have written. However, it would be advisable to be as concise as possible and stick to the descriptor in hand. I find that, if you are writing outside the boxes, there is generally room to put everything on the same page as the descriptor.
- Also, remember to **work in allowances for those ‘unseen’ amounts of energy** – like the time you need to dress, get breakfast and travel to and from work. All these have to be done to a timescale and a deadline that can drain your energy before you even begin a day’s work. If this is the case for you, you can explain the cumulative effect of minor daily living tasks on your symptoms in the “Other Information” section on [p.21](#).
- If all of this sounds daunting, do not worry, we will give examples below for each descriptor. Remember that these are only examples and not to be directly copied! You will need to explain how your condition affects you.

THE QUESTIONS

P.2 About You

This section is asking simple factual information and is self-explanatory.

P.3 If You Are Returning This Questionnaire Late

This section is asking if you are returning the questionnaire late and your reasons for doing so. As mentioned above, try your utmost not to return the questionnaire late. However, if that is absolutely unavoidable, then give as much detail as possible about why and back this up with medical evidence if your reasons are medically-related. An example could be a letter from your GP explaining that the extent

of your condition has prevented you from being able to complete the form within the timeframe and that you had to seek help to complete it.

P.4 About your General Practitioner (GP) or doctor's surgery

This section asks for details of your GP. It is worth saying here that, if your GP does not understand or believe in M.E., then it would be highly advisable to find one that does, as the DWP will probably contact your GP and what your GP tells them can affect your claim for benefit.

P.4 About other Healthcare Professionals, carers, friends or relatives who know the most about your disability, illness or health condition

The next section asks for details of other people who know the most about your conditions. This could be healthcare professionals such as an M.E. nurse, a consultant, a physio or OT, a social worker, a Personal Assistant / private healthcare professionals or alternative therapists, a carer, a friend or relative. If there is more than one person, write "continued on p.21" and then in the "Other Information" section on p.21 list the other people and their contact details.

Make sure you list people who do know the most about your conditions and are likely to give accurate information about how your day-to-day functioning and ability to carry out the descriptors is affected and ask their permission to put their name on your form. It is unlikely that the healthcare provider will contact them (they usually only make contact with the GP) but it is possible.

P.6 About your disabilities, illnesses or health conditions

Below is an example of how you might want to list your health conditions:

Myalgic Encephalomyelitis – started (put approximate year here) – this does not need to be the date it was diagnosed but rather the date you believe it started. Diagnosed (put approximate year here). Symptoms include: (list symptoms here). My condition is an invisible impairment which varies from hour-to-hour / day-to-day / week-to-week (include whichever statement is relevant to you). I use the following aids and adaptations as a result of my condition: (list aids and adaptations here).

You might also want to talk about the effect of cumulative activity here. For example:

My condition affects my ability to produce energy. As a consequence I have a limited amount of cognitive and physical energy available to me on a daily basis. I have to pace any physical or cognitive activity I attempt, breaking it into chunks with rest periods in between. If I do not do this I worsen all the symptoms listed above and the recovery period is prolonged, during which time my functioning reduces even further.

List all your health conditions, not just the M.E.. If you have POTS, depression or anxiety alongside the M.E. for example, list these separately as, while they may be a consequence of the M.E., they are still separate conditions. However, don't list your symptoms as separate conditions. List the symptoms under each health condition they relate to.

P.7 About your disabilities, illnesses or health conditions continued

In this section list the name, dosage and frequency of any medication you take and any side-effects. If you are not on stronger medication, it might be an idea to give a brief explanation as to why, for example:

previously tried anti-depressants / stronger pain medications but couldn't cope with the side-effects as I am drug-sensitive.

If you can get a healthcare professional to back up this statement in any evidence they give, it could help your case. The extent of medication you are on is often used as an indicator of the severity of your condition in assessments.

P.7 Hospital, clinic or special treatment like dialysis or rehabilitation treatment

In this next section put details of any hospital or clinic treatments you are having or are expected to have in the near future, eg adaptive pacing therapy, specialist physiotherapy, regular appointments with a specialist, regular appointments with a specialist M.E. nurse service, CBT, etc. If there is no local specialist M.E. service in your area, you might want to point this out here as the treatments you have and who you see can also be used by the healthcare provider to assess your level of impairment.

You could also mention past treatments you have had briefly such as,

previously attended pain management programme

or

have had extensive psychological input over the years (if you have accompanying mental health conditions alongside your M.E.).

If you have had treatment such as Graded Exercise Therapy for M.E. previously which has made your condition worse, you might want to state,

previous course of Graded Exercise Therapy for M.E. but treatment worsened my condition so had to stop.

If you were unable to engage in a course of treatment because of your conditions, you might want to say something like,

was advised to attend regular sessions at a pain management programme but my condition prevented me from being unable to attend / engage.

The remaining two sections under this heading on P.7 require factual information and should be self-explanatory.

THE DESCRIPTORS

The next section, on p8, is the start of the “descriptors”, ie the questions that you score points for. Pages 8-13 and are concerned with physical or sensory impairment, while pages 14-17 are concerned with mental, emotional or cognitive impairment. Page 18 is a stand-alone question which crosses over both physical and mental. This guide is M.E- specific but you can use the formula below to provide evidence on other conditions you have that may affect your ability to carry out the descriptors as well.

Part 1 – “Physical Disabilities”

P8, Q 1 – Moving around and using steps

Box 1

The first box in this question is about your ability to move from one point to another, either by walking (with or without aids) or by self-propelling a manual wheelchair. This descriptor is the

way that most people with M.E. get into the Support Group, so it is important to answer this clearly and accurately.

This isn't about the distance you could walk if you pushed yourself, it is about the distance you could walk repeatedly, at any given point of the day no matter how bad your symptoms are at that point (ie reliably), without significant after-effects, safely (ie without falling or walking into things) and in a reasonable time scale.

10 metres is about the length of a double decker bus – so when you are ticking a distance make sure that you think about how many bus lengths you could repeatedly walk or self-propel a manual wheelchair, without having to stop and without any after-effects, at any given point in the day. If it varies, tick this box.

Here is an example answer:

I am unable to self-propel a manual wheelchair at all due to the pain, debilitating fatigue and muscle weakness I experience as a result of my M.E.. My walking distance varies throughout the day, in accordance with the severity of my symptoms at any given point, which fluctuate from hour to hour. However, for over half the day I would be unable to repeatedly mobilise further than 50 metres due to pain, debilitating exhaustion, flu-like malaise, dizziness, difficulties with coordination and balance, unsteadiness on my feet, (list all your symptoms here that impair your walking ability) caused by my M.E.. During the times that I am able to mobilise further (the minority of the time), I experience an increase in (list symptoms that worsen after walking here), that lasts for at least (put length of time here) and requires me to have complete rest in silence and darkness in a supported lying position in order to recover.

If the walking distance you can walk repeatedly is less than 50 metres, particularly if it is 20 metres or less, write that distance instead of 50 metres, as it could be cross-referenced for a future PIP application.

Or you could write something like this:

There are times throughout the day every day / more days than not where I would be unable to repeatedly mobilise further than (put distance here) metres, due to (list symptoms here caused by my M.E.). Therefore I cannot reliably mobilise (put distance here) metres for over half the time.

When you are requesting supporting medical evidence, ask your healthcare professional to state the distance in their evidence that you can repeatedly, reliably and safely mobilise without significant after-effects and within a reasonable timescale.

Box 2

The next box is looking at your ability to go up and down two steps with a handrail. Most people with M.E. tell us they can do this. However, you need to be able to do it at will and repeatedly, as would be required in a work situation.

WE ask people to imagine that they are at work and the photocopier is up two steps, and every five minutes they have to walk up and down those two steps to go and photocopy something. In many cases, the answer changes from “I can walk up and down two steps” to “I could only do it a few times and there are times of the day where I would struggle to do it all.” If that is the case for you, state this here and state what symptoms would stop you / what symptoms would start to develop if you had to do it repeatedly or reliably.

An example of an answer might be something like this:

Whilst I could do this movement in isolation / one or two times, repetition would quickly drain me and exacerbate the symptoms of (list symptoms here) caused by the M.E.. I therefore would struggle to repeat this movement to the extent required for work-related activity. There are also times of the day more days than not where I can do nothing but rest in silence in a supported lying position, and at these times I would struggle to carry out this descriptor at all and attempting to do so, which is advised against at these times by my healthcare professionals, would worsen my symptoms and I would be unable to carry out even minor physical or cognitive activity for up to (state time here) minutes / hours / days afterwards.

Point scores for Moving Around and Using Steps

Descriptors	Points
<p>A. Cannot, unaided by another person, either:</p> <p>(i) Mobilise more than 50 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p> <p>(ii) Repeatedly mobilise 50 metres within a reasonable timescale because of significant discomfort or exhaustion.</p>	<p>15 points</p> <p><i>Admission into the support group if this descriptor applies</i></p>
<p>B. Cannot, unaided by another person, mount or descend two steps even with the support of a handrail.</p>	<p>9 points</p>
<p>C. Cannot, unaided by another person, either:</p> <p>(i) Mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p> <p>(ii) Repeatedly mobilise 100 metres within a reasonable timescale because of significant discomfort or exhaustion.</p>	<p>9 points</p>
<p>D. Cannot, unaided by another person, either:</p> <p>(i) Mobilise more than 200 metres on level ground without stopping in order to avoid significant discomfort or exhaustion; or</p> <p>(ii) Repeatedly mobilise 200 metres within a reasonable timescale because of significant discomfort or exhaustion.</p>	<p>6 points</p>
<p>E. None of the above applies.</p>	<p>0</p>

P.9, Q 2 – Standing and Sitting

The first test is assessing your ability to move from one seat to another unaided without help from another person.

You might want to talk about having to push down on something to get out of a chair, whether it's the arms of the chair, your legs or a walking stick. You might have false starts where you attempt

to get up and then sit back down again straight away due to dizziness or poor balance.

It might drain you of energy or cause you pain. These are the types of things you need to think about and state.

As with the previous descriptor, many people tell us they are fine doing this, until we give a work-place example. I might ask them to imagine that they are at a desk working but a new person has joined and they have to keep getting up out of their chair every 15 minutes or so and move into the next seat to show the new person what to do. Again, the answer turns from a 'yes' into a 'no', due to the fact that they cannot repeat the movement.

So a sample answer might be exactly the same as the example given for going up and down two steps above. You might find that you are repeating this answer throughout a lot of the descriptors. That is fine and necessary if it holds true for the other descriptors, so don't be frightened to do so.

The next test in this section is looking at how long you can remain at a work-station with a combination of sitting and standing. Think about how long you can stand up for and think about how long you could sit for in a straight-backed chair with no arms, as you might be required to do at a work station.

Then think about whether you could maintain that duration repeatedly throughout the day or whether there are times of day you would have to sit slouched or semi-reclined or even lie down due to your symptoms.

A sample answer might be:

I can stand for about 10 minutes before I get pain in my legs, I start to feel dizzy, my balance goes and my fatigue worsens considerably.

If I have to sit in a straight-backed chair for longer than 15 minutes, my pain and fatigue increase, I get cold and feel like I'm shaking internally and I experience flu-like malaise.

So the length of time I could remain at a work station with a combination of standing and sitting without causing a significant increase in symptoms is 25 minutes.

There are also times of day every day where I have to lie in a supported resting position to avoid further exacerbation of my symptoms and at these times I would be unable to safely and reliably remain at a work station.

If the time you remain at a work-station is longer, but you cannot do so reliably and repeatedly, you might want to say something like:

I can sometimes stay at a work station for longer than 30 minutes. However, this is the minority of the time and I cannot do so repeatedly or at will because of the way that my symptoms of (list symptoms here) caused by the M.E. fluctuate throughout the day. Also, when I do so it exacerbates my (list symptoms here that are exacerbated by standing for longer) and it can take up to (insert figure) minutes / hours / days for those symptoms to calm down.

Point scores for Standing and Sitting

Descriptors	Points
A. Cannot move between one seated position and another seated position which are located next to one another without receiving physical assistance from another person.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot, for the majority of the time, remain at a work station: (i) standing unassisted by another person (even if free to move around); (ii) sitting (even in an adjustable chair); or (iii) a combination of paragraphs (i) and (ii) for more than 30 minutes, before needing to move away in order to avoid significant discomfort or exhaustion.	9 points
C. Cannot, for the majority of time, remain at a work-station: (i) standing unassisted by another person (even if free to move around). (ii) sitting (even in an adjustable chair); or (iii) a combination of paragraphs (i) and (ii) for more than an hour before needing to move away in order to avoid significant discomfort or exhaustion.	6 points
D. None of the above applies.	0

P9, Q 3 – Reaching

This question is assessing whether you can reach up with either arm, above waist height. Different points are awarded depending on how high you can lift your arms.

Again, most people tell me they can do all of the movements asked about in the descriptor, but when I put them into a work context, such as stacking shelves or filing, the answer turns into a 'no'.

One of the main reasons that people with M.E. struggle with these movements is because they cannot sustain or repeat them. So think about whether you have any difficulties holding your arms up for long enough to wash, dry or brush your hair for example. Do you have difficulty looking through your clothes in the wardrobe, hanging washing on the line or putting dishes away in a cupboard above waist height?

A sample answer might look like very similar to the previous examples, but you might want to include information here about not just repeating this movement, but sustaining it for long enough to carry out a task due to your limbs feeling leaden due to the fatigue and weakness caused by the M.E. or it might be pain that impedes your ability to do this.

Point scores for Reaching

Descriptors	Points
A. Cannot raise either arm as if to put something in the top pocket of a coat or jacket.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot raise either arm to top of head as if to put on a hat.	9 points
C. Cannot raise either arm above head height as if to reach for something.	9 points
D. None of the above applies	0

P10, Q 4 – Picking up and moving things – using your upper body and either arm

This question assesses your ability to pick up items such as a one- pint carton of liquid, a two-pint (litre) carton of liquid or a light large object such as an empty cardboard box. Think about the movements involved.

Do you have co-ordination difficulties that leave you prone to dropping, spilling or knocking things over when you try to move them? Does this happen more often than not? Do you have muscle weakness or reduced grip due to the fatigue caused by the M.E. that would make these movements difficult? Does picking up and moving something cause you pain, fatigue, breathlessness or dizziness?

If you can do these movements once, could you do them repeatedly? For example, if you worked on a checkout or a production line and had to repeatedly pick up and move objects of this type?

When you think about moving a cardboard box, your arms will be further apart and you may have to twist your body to pick it up and move it. Do you have pain or back problems that would make this movement difficult? Could you do it repeatedly? Are there similar large but light items that you have difficulty moving such as a pillow from one side of the bed to another?

Are there times of day you couldn't do these movements at all? How many times or for how long do you think you would be able to do these movements before you began to exacerbate your cognitive or physical M.E. symptoms? How long would it take you to recover? Which symptoms would you exacerbate?

Point scores for Picking up and moving or transferring by use of the upper body and arms

Descriptors	Points
A. Cannot pick up and move a 0.5 litre carton full of liquid.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot pick up and move a one litre carton full of liquid.	9 points
C. Cannot transfer a light but bulky object such as an empty cardboard box.	6 points
D. None of the above applies	0

P.10, Q 5 - Manual dexterity (using your hands)

This question is assessing whether you have difficulties using your hands to press, turn, pick up and manipulate objects. If you can't do it with one hand, can you do it with the other? Can you do some movements but not others? Which ones can't you do and why? If you can do all of them, is it time-limited or can you do them repeatedly? For example, most people we see cannot hold a pen for long enough to complete the ESA50 questionnaire in one go.

Imagine you were at work, working in a change counter in an amusement arcade. How long could you keep picking up and manipulating change before it exacerbated your symptoms or your coordination started to go and you started to drop things? Would you get tremors, pain, spasms or reduced grip, the more you tried to push on through?

Is your time on a keyboard or mouse limited due to muscle fatigue from minor repeated movements? You might have examples around manipulating buttons, zips or laces when getting dressed. You might have an adapted car because of your problems with dexterity. You might have a problem gripping your key to get through the front door when your symptoms flare up.

Your answer might be something like,

While I can do all of these movements, repetition of them would quickly exacerbate my symptoms of pain, fatigue and flu-like malaise and my coordination and dexterity would quickly worsen, so I would be unable to carry these movements out with the degree of repeatability required for work-related activity.

In addition, there are times of the day where I can do nothing other than rest in silence in a supported lying position because of the extent of my symptoms / in order to avoid further exacerbation of symptoms, so at these times I would be unable to repeatedly and reliably carry out any of these movements.

Point scores for manual dexterity

Descriptors	Points
A. Cannot press a button (such as a telephone keypad) with either hand and cannot turn the pages of a book with either hand.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot pick up a £1 coin or equivalent with either hand.	15 points
C. Cannot use a pen or pencil to make a meaningful mark with either hand.	9 points
D. Cannot single-handedly use a suitable keyboard or mouse.	9 points
E. None of the above applies.	0

P.11, Q 6 – Making self understood through speaking, writing, typing, or other means which are normally or could reasonably be used, unaided by another person.

This descriptor is assessing your ability to convey a simple message by any of the above means. I ask people to imagine that they are at their most brainfogged moment of the day and they have dropped some water on the floor. Could they then tell someone who walked in the room to be careful as there is water on the floor?

It is rare that we see someone with M.E. score points either in an ESA assessment or a PIP assessment for communicating. However, it is still worth describing whether you can communicate in a sustained and repeated way as would be required in a work-related situation and also about the after-effects.

For example, you might be able to communicate for an hour or two at a time within a day, but that might leave you unable to communicate reliably or repeatedly for the rest of the day and you may have to rest in silence until you have recovered from the exacerbation of symptoms it has caused. If this is the case, you would not be able to repeatedly and reliably communicate for 16 hours or more in a working week.

Explain what would happen if you tried to push past your limit.

Perhaps it is a feeling like someone is squeezing your brain inside your head, electric shock type sensations, internal tremors or you might lose the inability to express yourself, have difficulties with word finding, etc. Does your mind start to go blank? Do you forget what you meant to say or what you were in the middle of saying? How long would it take you to recover?

Point scores for making self understood through speaking, writing, typing, or other means which are normally or could reasonably be used, unaided by another person

Descriptors	Points
A. Cannot convey a simple message, such as the presence of a hazard.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Has a significant difficulty conveying a simple message to strangers.	15 points
C. Has some difficulty conveying a simple message to strangers.	6 points
D. None of the above applies	0

P.11, Q 7 – understanding communication by: (i) verbal means (such as hearing or lip reading) alone; (ii) non-verbal means (such as reading 16-point print or Braille alone; or (iii) a combination of sub-paragraphs (i) and (ii), using any aid that is normally or could reasonably be used, unaided by another person.

This descriptor assesses your difficulties in understanding either written or verbal communication. There might be times of day where you cannot process verbal or written information or where you can – but brainfog and fatigue exacerbation makes it physically hurt to do so.

Do you have to take someone with you to appointments or record things because you phase out and miss important information? Do you have to ask people to repeat themselves? Are there times of day where your brainfog is so bad that you wouldn't attempt a conversation or a phonecall or to read a let-

ter? Can you read or listen for a short duration, but any longer becomes problematic? How long? What symptoms prevent you from continuing? Do you use a screen reader, other voice-activated software, a magnifier or audio books to read?

Point scores for understanding communication by: (i) verbal means (such as hearing or lip reading) alone; (ii) non-verbal means (such as reading 16-point print or Braille alone; or (iii) a combination of sub-paragraphs (i) and (ii), using any aid that is normally or could reasonably be used, unaided by another person.

Descriptors	Points
A. Cannot understand a simple message, such as the location of a fire escape, due to sensory impairment.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Has significant difficulty understanding a simple message from a stranger due to sensory impairment.	15 points
C. Has some difficulty understanding a simple message from a stranger due to sensory impairment.	6 points
D. None of the above applies	0

P.12, Q 8 – Navigation and maintaining safety using a guide dog or other aid if either or both are normally used or could reasonably be used.

This descriptor is about your visual ability to get around safely. It is not assessing your cognitive or physical ability to get around. Do you get blurred vision at points in the day, floaters or have a visual impairment that affects your ability to see to get around safely and reliably? If so, state that here.

Point scores for navigation and maintaining safety using a guide dog or other aid if either or both are normally used or could reasonably be used.

Descriptors	Points
A. Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment.	15 points
B. Cannot safely complete a potentially hazardous task such as crossing the road, without being accompanied by another person, due to sensory impairment.	15 points
C. Unable to navigate around unfamiliar surroundings, without being accompanied by another person, due to sensory impairment.	9 points
D. None of the above applies	0

P.12, Q 9 – Absence or loss of control whilst conscious leading to extreme evacuation of the bowel and / or bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally or could reasonably be worn or used.

People often shy away from this descriptor, which is assessing whether you have your voiding of either

bladder or bowel that is extensive enough to require a wash or change of underwear, despite using aids such as pads or a stoma or catheter. However, if you do have bladder issues, which many people with M.E. do, being honest could put you in the Support Group. Remember to include information about frequency here.

Point scores for absence or loss of control whilst conscious leading to extreme evacuation of the bowel and / or bladder, other than enuresis (bed-wetting), despite the wearing or use of any aids or adaptations which are normally or could reasonably be worn or used.

Descriptors	Points
A. At least once a week experiences: (i) loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder; or (ii) substantial leakage of the contents of a collecting device, sufficient to require cleaning and a change in clothing.	15 points <i>Admission into the support group if this descriptor applies</i>
B. The majority of the time is at risk of loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder, sufficient to require cleaning and a change of clothing, if not able to reach a toilet quickly.	6 points
C. Neither of the above applies.	0

P.13, Q 10 – Consciousness during waking moments

This descriptor assesses whether you have episodes of loss or altered consciousness, such as fits, faints or blackouts. Even if these are not frequent, if they are unpredictable it may still warrant some points as you do not know when it is going to happen. It does not include falling asleep.

The law states that altered consciousness may include clouding of mental faculties resulting in loss of control of thoughts and actions.

In reality, it is very difficult for someone with M.E. to score points on cognitive descriptors. However, if you believe that your cognitive dysfunction becomes so bad that it affects you to this extent, it would be worth mentioning here.

Point scores for consciousness during waking moments

Descriptors	Points
A. At least once a week has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.	15 points <i>Admission into the support group if this descriptor applies</i>
B. At least once a month has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.	9 points
C. None of the above applies	0

Part 2 - "Mental, cognitive and intellectual function"

In reality, people with M.E. rarely score points on cognitive tasks in benefit assessments, despite having medical evidence stating they have cognitive issues. The ME Association are currently in talks with Parliament to try and address this.

Just because this is the case, however, it does not mean you shouldn't put any cognitive issues down. Remember to talk about the problems you would have with performing a descriptor reliably and repeatedly, to the degree that would be required in a work-related situation, and also about any after-effects of performing that descriptor.

Remember that you are being assessed on your ability to carry out that descriptor for 51% of the time or more. If you could carry out a descriptor only 49% of the time, you should be assessed as being unable to carry out that descriptor.

P.14, Q 11 - Learning Tasks

This descriptor looks at your ability to learn and retain information to allow you to carry out a specific a task. If you have to read instructions every time you do that task or be shown more than once, then you have not learnt the task. As with the descriptors around physical impairment, pain, fatigue or other symptoms that you experience in performing any of the cognitive descriptors in a repeated manner, to the degree required in a work-related environment, should be taken into account, as should increasing difficulty in performing the descriptor during or after repetition.

Point scores for learning tasks

Descriptors	Points
A. Cannot learn how to complete a simple task, such as setting an alarm clock.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot learn how to complete a simple task, such as setting an alarm clock.	9 points
C. Cannot learn anything beyond a moderately complex task, such as the steps involved in operating a washing machine to clean clothes.	6 points
D. None of the above applies.	0

P.15, Q 12 – Awareness of Everyday Hazards

This descriptor is about your ability to recognise that something is dangerous or to recognise potential hazards. Are there are times of day when the brainfog is so bad that it might prevent you from analysing whether something is hot before touching it, for example picking up something hot in the kitchen without something to protect your hands from the heat or not noticing if there is something lying on the floor that you could trip over.

Point scores for awareness of everyday hazards

Descriptors	Points
A. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or (ii) damage to property or possessions such that the claimant requires supervision for the majority of the time to maintain safety.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or (ii) damage to property or possessions such that the claimant frequently requires supervision to maintain safety.	9 points
C. Reduced awareness of everyday hazards leads to a significant risk of: (i) injury to self or others; or (ii) damage to property or possessions such that the claimant occasionally requires supervision to maintain safety.	6 points
D. None of the above applies.	0

P.15, Q 13 – Initiating and completing personal action

This descriptor is looking at your ability to initiate a task, involving planning, organisation, problem solving or switching tasks. This is not looking at your physical ability to complete a task, rather any cognitive or mental difficulties you might have with the descriptor.

For example, if you experience depression alongside M.E., you may have difficulty with motivation to even start a task. Or you may be able to start a task but brainfog prevents you completing it within a reasonable timeframe. You may have to break tasks up because of this and do bits at a time.

You might have difficulty thinking clearly enough to plan and organise what you need to do or to solve a problem. You might find you get easily distracted or forget what you were doing if you get interrupted. Many tasks will require planning and organising.

For example, with cooking you would need to make a decision about what to eat, make sure you have the right ingredients to hand and be able to coordinate timings so that everything is cooked at the right

time, possibly follow a sequence of instructions if using a recipe, etc. Would you get distracted in the middle of cooking or forget you'd left something on the stove?

In order to get into the support group you must be unable to either mentally or cognitively complete two tasks, one after another, within a reasonable time frame. Remember to note any after-effects of trying to carry out two cognitive tasks, one after another.

Point scores for Initiating and completing personal action

Descriptors	Points
A. Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions for the majority of the time.	9 points
C. Frequently cannot, due to impaired mental function, reliably initiate or complete at least two sequential personal actions.	6 points
D. None of the above applies	0

P.16, Q 14 – Coping with Change

This descriptor looks at whether changes to your normal routine make life “significantly more difficult” or unmanageable.

Think about both planned or unplanned changes. Think about how a change to your pacing schedule would make life much more difficult or unmanageable, both physically and cognitively.

If someone turned up unexpectedly when you were supposed to be resting and you had to communicate with them, would you be left so brainfogged afterwards that you would be unable to communicate with anyone else for a period of time? I

f you experience anxiety alongside M.E., the slightest change, even planned in advance, may increase your anxiety.

(Point score box on next page).

Point scores for coping with change

Descriptors	Points
A. Cannot cope with any change to the extent that day-to-day life cannot be managed.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Cannot cope with minor planned change (such as pre-arranged change to the routine time scheduled for a lunch break) to the extent that, overall, day-to-day life is made significantly more difficult.	9 points
C. Cannot cope with minor unplanne change (such as pre-arranged change to the routine time scheduled for a lunch break) to the extent that, overall, day-to-day is made significantly more difficult.	6 points
D. None of the above applies	0

P.16, Q 15 – Getting About

This descriptor looks at your ability to travel without support from another person. This could be due to anxiety, depression or other mental health difficulties. It could also be due to difficulties with following and planning a route of a journey cognitively.

How would you cope if there was a replacement bus or a diversion to a route or a change to a bus or rail service for example? Would you be able to remember directions if you had to ask the way?

Remember to talk about mental or cognitive difficulties getting to both familiar and unfamiliar places unaccompanied. This descriptor is not looking at your physical ability to get out and about.

Point scores for getting about

Descriptors	Points
A. Cannot get to any place outside the claimant's home with which the claimant is familiar.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Is unable to get to a specified place with which the claimant is familiar, without being accompanied by another person.	9 points
C. Is unable to get to a specified place with which the claimant is unfamiliar, without being accompanied by another person.	6 points
D. None of the above applies	0

P.17, Q 16 – Coping with Social Engagement

This looks at your mental and cognitive ability to engage with other people – if you have difficulty communicating for significant periods of time due to brainfog, word-finding difficulties, short-term memory problems, poor concentration, etc. However, if you are able to answer your assessor’s questions at assessment, you are generally assessed as being fine with social engagement.

Remember to talk about the difficulties of engaging repeatedly or reliably with respect to your cognitive ability to do so, not your physical ability. If engaging socially drains you, you can talk about how it worsens your other symptoms. If you have anxiety or depression, or have lost confidence around people, you might become isolated. If you have lost confidence around people, it must be “significant”; not just “shyness” or “reticence”.

Point scores for coping with social engagement

Descriptors	Points
A. Engagement in social contact is always precluded due to difficulty relating to others or significant distress experienced by the claimant.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Engagement is social contact with someone unfamiliar to the claimant is always precluded due to difficulty relating to others or significant distress experienced by the claimant.	9 points
C. Engagement in social contact with someone unfamiliar to the claimant is not possible for the majority of the time due to difficulty relating to others or significant distress experienced by the claimant.	6 points
D. None of the above applies	0

P.17, Q 17 – Appropriateness of Behaviour Engagement

This descriptor is about your ability to control your behaviour “in an average workplace setting”. This could be as a result of a mental health condition.

Point scores for appropriateness of behaviour engagement

Descriptors	Points
A. Has on a daily basis uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any work place.	15 points <i>Admission into the support group if this descriptor applies</i>
B. Frequently has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any work place.	15 points
C. Occasionally has uncontrollable episodes of aggressive or disinhibited behaviour that would be unreasonable in any work place.	9 points
D. None of the above applies	0

Part 3 – Physical and Mental

P.18, Q 18 – Conveying food or drink to the mouth/chewing or swallowing food or drink

This looks at the effect of either your mental, physical or cognitive health on your ability to eat and drink. It's not about your ability to prepare food or drink – rather your ability to get it to your mouth and chew / swallow it.

Consider whether it takes you an unreasonable time to eat a meal because you have to keep stopping or resting, or whether there are times of day you wouldn't be able to convey food or drink to your mouth because your symptoms are so bad at that time. You might be unable to pick up your glass at times and have to use a straw, which might not be very effective. Do repeated movements worsen pain, fatigue, dizziness, etc?

You may also have depression and need prompting to eat or drink as you have no motivation.

Point scores for conveying food or drink to the mouth/chewing or swallowing food or drink

Descriptors	Points
<p>A. Cannot convey food or drink to the claimant's own mouth without receiving physical assistance from someone else;</p> <p>B. Cannot convey food or drink to the claimant's own mouth without repeatedly stopping or experiencing breathlessness or severe discomfort;</p> <p>C. Cannot convey food or drink to the claimant's own mouth without receiving regular prompting given by someone else in the claimant's presence; or</p> <p>D. Owing to a severe disorder of mood or behaviour, fails to convey food or drink to the claimant's own mouth without receiving;</p> <p>(i) physical assistance from someone else; or</p> <p>(ii) regular prompting given by someone else in the claimant's presence.</p> <p>E Cannot chew or swallow food or drink;</p> <p>F. Cannot chew or swallow food or drink without repeatedly stopping, experiencing breathlessness or severe discomfort;</p> <p>G. Cannot chew or swallow food or drink without repeatedly receiving regular prompting given by someone else in the claimant's presence; or</p> <p>H. Owing to a severe disorder of mood or behaviour, fails to</p> <p>(i) chew or swallow food or drink; or</p> <p>(ii) chew or swallow food or drink without repeatedly receiving regular prompting given by someone else in the claimant's presence.</p>	<p>15 points</p>

P.19 – Face-to-face assessment

This question is about help you might need to attend a face-to-face assessment. When answering, bear in mind that you not only have to deal with getting to an assessment centre, but also a potential wait of an hour or more to be seen sat upright in a straight-backed chair, possibly without arms, in a potentially busy and noisy assessment centre with strip lighting. You then have to get through the assessment itself, which can last up to an hour (although typically it is usually around half an hour). You then have the journey home.

If you feel that having to go to an assessment centre would set your condition back considerably, and you can get medical evidence to support this, you can write here that you would like to request a home visit – a healthcare professional from the DWP’s chosen healthcare provider will then decide whether your condition is severe enough to warrant a home visit.

You might also want to ask for the assessment to be recorded, for somewhere with accessible parking close to the entrance, for the healthcare professional who is assessing you to be of the same gender as you, for a ground floor room, an accessible toilet nearby, or for someone to attend with you.

If your supporting evidence is strong enough and you have filled your form in clearly, you may not require a face-to-face at all. *See page 9, “Relevant Supporting Information”.*

P.20 – Self explanatory factual information.

P.21 – Other Information

If you already receive PIP, you might want to write this in here. While it is a different benefit, it will give a better picture of your limitations.

If you have had to get help to complete the form, you can state that here, or if it has taken you a long time or you have had to do a little bit over several weeks.

If you have any continuations from previous questions, they can go on this page as well.

You might want to mention that your condition means that your cells cannot make energy efficiently and that results in you having limited cognitive and physical energy available for even basic tasks of daily living. You might want to explain the cumulative effect of activity on your symptoms, or use the analogy of a mobile phone where the battery never charges fully, drains after a very short time and takes hours of recharging to get back to where it was.

Regulation 35 for ESA and paragraph 4, schedule 9 of the Universal Credit regulations state that, even if someone does not score enough points to pass the limited capability for work-related activity test, they may be treated as such if they can show that “the claimant suffers from some specific disease or bodily or mental disablement” and that, as a result, “there would be a substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work-related activity”. This encompasses risk to self or others. This is called the “Exceptional Circumstances” rule.

If you can get medical evidence to show that work-related activity would cause a substantial risk to your physical or mental health, then you should argue that you should be assessed under either of these regulations as having limited capability for work-related activity.

Regulation 29 for ESA and paragraph 4, schedule 8 of the Universal Credit regulations state that, even if

someone does not score enough points to pass the limited capability for work test, that you may also be assessed as having limited capability for work under the “Exceptional Circumstances” rule.

Again, be aware of the difference. “Limited capability for work” means you would still have to undertake “work-related activity” to move you closer to the labour market, whereas being assessed as having “limited capability for work-related activity” means you would not be required to undertake any work-related activity. Any reasonable adjustments an employer could potentially make will be taken into account here when assessing under this rule.

P.22 – Declaration, date and details of the person who completed the form

Please remember to sign and date your form. If someone else has completed the form, they will need to put their details here.

Part 3 – The Face-to-Face Assessment

We wanted to conclude this guide with some brief advice about the face-to-face assessment.

Preparing for the assessment

- Try to take someone with you and for someone to support you to get there and back. You will be asked at the assessment how you got there and assumptions will be made if you got there yourself. Don't forget, you not only have to deal with getting to an assessment centre, but also a potential wait of an hour or more to be seen sat upright in a straight backed chair, possibly without arms, in a potentially busy and noisy assessment centre with strip lighting. You then have to get through the assessment itself, which can last up to an hour (although typically it is usually around half an hour). You then have the journey home.
- Ask for your assessment to be recorded. This should be done on your claim form but again over the telephone as soon as you receive your appointment. Call the number on your appointment letter to check this is in place.
- You can change your face-to-face assessment appointment once only. If your request for a home visit is denied, back it up with medical evidence and ask for your request to be looked at again. An experienced welfare rights adviser may be able to assist you in changing the decision.

At the assessment

- Be prepared to answer questions about your typical day. You need to describe in detail the difficulties you have from the moment your eyes open and the symptoms that cause those difficulties.
- If you are asked about hobbies and interests, be sure to explain about how your symptoms create variability in your ability to do these things and about any assistance you need and any after-effects. For example, you may like playing the guitar but, if you state this, assumptions will be drawn that you can do this whenever you like, whilst the reality might be that you can only attempt this once a month.
- You will be asked when the last time you worked was, why you stopped and what you did for a job.
- You will be asked about whether you live on one or more floors, possibly where the toilet is and who lives with you. If you have difficulty going up and down stairs and have to limit your trips, mention that here.

- You will be asked if you have any pets. If you are unable to look after the pet or walk the pet, make it clear that someone else looks after it otherwise assumptions will be drawn.
- As stated earlier in this guide, the most common way people with M.E. are scored as having limited capability for work-related activity is via the mobility descriptor. You will be asked detailed questions of where you walk to. You might be asked if you go to the supermarket, to assess if you can walk the distance of a supermarket. You might be asked how you get on at hospital appointments. You might be asked how long you can walk for without stopping, or how far.
- The answers to these questions can often give misleading information so ensure you give full details about the distance you could walk reliably and repeatedly for over half the time, the length of time it takes you to walk a particular distance and how many stops you have to make if asked specifics about a particular walk, after-effects and how long it takes you to recover from them.
- You will be asked about all of the descriptors unless the healthcare professional feels they have enough evidence to assess you as having limited capability for work-related activity from the mobility descriptor alone. As stated in section 2 of this guide, it's important to talk about your ability to carry out each descriptor in a work-related scenario, ie taking into account how well you can do something, how often you can do something, if you need any help to do it, if you can do it reliably, safely and sustainability, the after-effects and recovery time of attempting a descriptor.
- Be aware that assumptions are often made from movements such as picking up a handbag, handling papers or even propping up your glasses so we cannot stress how important it is to get across fluctuation and sustainability, particular if you are asked to perform a set of movements during the assessment.
- You will be asked about each condition, medications and who you see for that condition. Observations will be made here regarding short-term memory and concentration. A prescription list can be useful to hand the healthcare professional. Assumptions may be drawn if you do not have much medication or medical input, so make it clear why that is the case. For example, there may be no specialist services in your area or you may have accessed your full quota of appointments already. Make this clear.
- Observations will also be made about eye contact, appearance, etc. Some people go into their assessment making an effort with their appearance that they wouldn't usually make or they might take extra pain medication or anxiety medication to get them through the assessment. It is important that the healthcare professional sees you as you would usually be, so these coping mechanisms can be counter-productive.
- Another thing that people have a tendency to do is to put a positive spin on their condition. Again, this will do you no favours in an assessment. As distressing as it is, you need to explain your reality so that the healthcare professional gets as accurate a picture as possible.
- Your healthcare professional will spend most of the assessment typing up answers into a computer programme, which is designed to enable them to score you points for each descriptor.
- At the end of the assessment you may be asked to complete some movements. These are "voluntary". If you know a particular movement will cause an issue, you need to state that. Do not do anything that will worsen your condition or put you at risk. If you attempt a movement and it causes a symptom, explain that. You have an invisible impairment so the healthcare professional will be none the wiser unless you make it clear when something causes discomfort.

FINAL WORDS

It can be an emotionally challenging exercise focusing on all the things that you can no longer do because of your health impairment in order to get the benefits you are entitled to. There are two points to remember here:

1)

It is not your fault that you developed a neurological condition which affects both your brain and body. Do not blame yourself. Be nice to yourself and seek out emotional support wherever you can to get you through the process.

Once the assessment process is out of the way, you can focus on the positives and what you can do and remember that your life still has value and meaning.

2)

National Insurance Contributions are paid as exactly that – insurance to cover you should you fall ill. So do not feel like you are taking handouts or charity or taking money away from others.

Many people with M.E. compare their condition with other impairments but in many cases, particularly with severe M.E., all the reasonable adjustments, aids and adaptations in the world may make no difference to their level of functionality because of the nature of the condition, whereas with other impairments it may.

We wish you the best of luck with the process!