

# PERSONAL INDEPENDENCE PAYMENT

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A GUIDE TO  
APPLICATIONS  
FOR PEOPLE  
WITH ME/CFS

DECEMBER 2022



# PERSONAL INDEPENDENCE PAYMENT

## A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

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This guide to **Personal Independence Payment** was written by Ella Smith, Welfare Rights Adviser at The ME Association.

Ella has been a welfare rights advisor since 2006 and has spent the majority of the time since on helping people struggling with benefits issues. She aims to make understanding the process easier and to give people with ME/CFS the toolkit they need to get the help they deserve.

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### 1: INTRODUCTION

**Please make an application for Personal Independence Payment (PIP). It is the main disability benefit and can help you to live a more comfortable life. ME/CFS is a recognised disability and long-term medical condition, so don't worry that you might be at a disadvantage because of this particular diagnosis.**

We appreciate that you might be hesitant about making a claim and for perfectly understandable reasons. Some of these could include:

- not wanting to admit to yourself and to others that you have a disability,
- that you need help and support and have to apply for benefits,
- a fear of the application process and of a medical assessment,
- the stigma that benefits claimants can attract in society,
- that you will not be believed,
- that your application could result in an unfavourable decision.

Please don't let these concerns put you off. You are just as entitled to PIP as any other person who is disabled. Unfortunately, you will have to accept the application process can be difficult. It is a departure from your routines and will require energy and focus.

Seek help from someone who knows you well, from Citizens Advice, by appointing a representative, or getting a home visit for the medical assessment, etc. – see below.

If you have to complete the process yourself, then work through the main form slowly by doing a little bit more each day and taking care of yourself as best you can. Remember: it is not your fault that you are disabled and in need of this benefit.

We have produced this guide to help demystify the process and reduce any concerns you might have. Trying to make a claim while battling ME/CFS can be hard, but it shouldn't put you off from trying. We wish you every success with your application and hope you receive an appropriate award.



**Personal Independence Payment (PIP) is the main disability benefit and can help you to live a more comfortable life. Please do make an application for PIP.**

# PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### PIP can help with extra living costs if you have:

- a long-term physical or mental health condition or disability, and,
- difficulty doing certain everyday tasks or getting around because of your condition.

### There are 2 parts to PIP:

- a daily living part - if you need help with everyday tasks and,
- a mobility part - if you need help with getting around.

Whether you get one or both parts and how much you get depends on how difficult you find everyday tasks and getting around.

<https://www.gov.uk/pip/how-much-youll-get>

You can get PIP even if you're working, have savings or are getting most other benefits. Because disabled people's needs vary so much, PIP gives you control over how to spend any award.

If your claim is successful, you'll receive a payment every four weeks and can spend it on the help and support that you feel is most needed.

### a. Daily living

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

- eating, drinking, or preparing food,
- washing, bathing, and using the toilet,
- dressing and undressing,
- reading and communicating,
- managing your medicines or treatments,
- making decisions about money,
- socialising and being around other people.

### b. Mobility

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.



### MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

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.

### c. How difficulty with tasks is assessed

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 reliably,
- how long it takes you,
- how often your condition affects this activity,
- whether you need help to do it, from a person or using extra equipment.

### More information

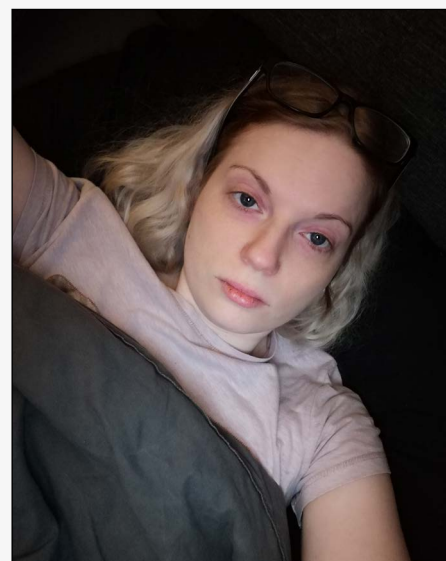
- **Gov.UK:** Personal Independence Payment:

<https://www.gov.uk/pip>

### d. The Application Process

PIP is like other sickness and disability benefits and can be a complicated process. It will require a detailed form ('How your disability affects you') to be completed, evidence to be obtained, and medical assessments to be attended and usually a medical assessment conducted by an independent healthcare professional.

- If you are unable to complete the process by yourself or travel to a medical assessment, you can appoint someone to be your representative and ask for the assessment to happen in your home.
- This might be especially useful if you are severely or very severely affected, but there are procedures that you and your representative should be aware of before seeking this appointment.



PIP does not separate your needs into day and night needs, rather it is considered over a 24-hour period.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

If you can complete some of the application form but need help to complete it in full within a set timeframe, you can ask for an extension.

You can use a computer and then add additional printed sheets (allowing you to use speech-to-text if necessary). Be sure to include the name and signature of the person who helped you, along with your own, before submitting the form.

- You may be able to get a home visit from a DWP (Department for Work and Pensions) officer to help with your benefit claim. This might be useful for people severely or very severely affected who cannot complete the process themselves, or who live alone, or are reliant on the care of someone else, or who are in hospital.

- You cannot book a visit yourself. Tell the DWP you need help to claim benefits by calling the number of the benefit you're applying for. If you're eligible, they'll arrange a support visit.

- **Gov.UK:** Support visits if you need help to claim benefits:

<https://tinyurl.com/zcjytf3v>

Most assessments are now conducted remotely as a matter of course; usually by telephone with a small number of video assessments. If the type of assessment offered is unsuitable due to your needs then contact the assessment company and ask for an alternative form of assessment, explaining your needs and backing this up with evidence (such as a GP letter) if you have any.

### More information

The following are recommended general guides to making a claim for PIP:

1. **Scope (a UK charity):** Personal Independence Payment Guide:

<https://tinyurl.com/2pu89bpx>

2. **Disability Rights UK:** Personal Independence Payment Guide:

<https://tinyurl.com/yckejn4u>



### DISCLAIMER:

The ME Association is unable to provide personalised benefits advice. We do however aim to provide guidance to the kind of welfare benefits that people with ME/CFS and those who care for them might be entitled to. The guidance that we give and any signposting to external sources is for information only and is not a recommendation. The ME Connect telephone helpline can also signpost callers to external sources of benefits information and to free sources of advice. We cannot be held responsible should individuals decide to engage any service that charges a fee for advice or representation, and it is important they complete their own research before seeking such help.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### 2: HOW IS PIP AWARDED AND WHAT COULD I GET?

PIP has two components: the daily living part and the mobility part. Each is paid at two different levels – a standard rate and an enhanced rate.

Like Employment and Support Allowance, your eligibility for PIP is assessed using a points system. The DWP use a set of statements called 'descriptors' to work out the level of difficulty you have with a variety of activities.

The evidence used to decide each descriptor is based on a combination of the information you provide on the 'How Your Disability Affects You' form, a medical assessment by an independent healthcare professional, and any other relevant evidence that you submit – such as supporting letters from your doctor, ME/CFS specialist service, carer, or social worker, for example.

All this evidence is reviewed by a case manager at the DWP who will choose which descriptor matches the evidence and then award points accordingly.

A minimum of eight points needs to be achieved in either Daily Living or Mobility to be awarded a PIP component. If 12 or more points are awarded, then an enhanced rate of benefit is payable.

#### As of April 2022, current rates of PIP are:

- Daily Living Standard Rate (8 – 11 points): £61.85 weekly
- Daily Living Enhanced Rate (12+ points): £92.40 weekly
- Mobility Standard Rate (8 – 11 points): £24.45 weekly
- Mobility Enhanced Rate (12+ points): £64.50 weekly

Payment is every 4 weeks in arrears by the DWP to your nominated bank account. Please note that claim-processing times can vary depending on region, type of assessment and ease of assessing based on evidence. Please be aware that it is normal to have to wait for months for a decision.

#### CASE STUDY

Raul applies for PIP and is awarded 13 points for Daily Living and 6 points for the Mobility activity descriptors. He receives an award of Enhanced Daily Living component but nothing for the Mobility component as he has not achieved the minimum of 8 points required.

#### CASE STUDY

Susan applies for PIP and is awarded 4 points for Daily Living and 4 points for the Mobility activity descriptors. She is not awarded any PIP component as, although she has achieved 8 points, these are spread over both components and the threshold for each component is a minimum of 8 points.

#### CASE STUDY

Jennifer's parents apply for PIP as her appointed representatives because she is very severely affected, unable to leave her bed, and requires 24-hour care. She receives a medical assessment at home and is awarded 76 points for Daily Living and 24 points for the Mobility activity descriptors. She receives enhanced components for both and the maximum payment amount.





## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

The DWP case manager will decide on the length of the award when making the decision. The DWP will review every award periodically to make sure that the level of help is still correct. This could vary from anywhere between 18 months for a short-term award to a 10-year 'light-touch' review of very serious or long-term conditions where the prognosis is unlikely to vary.

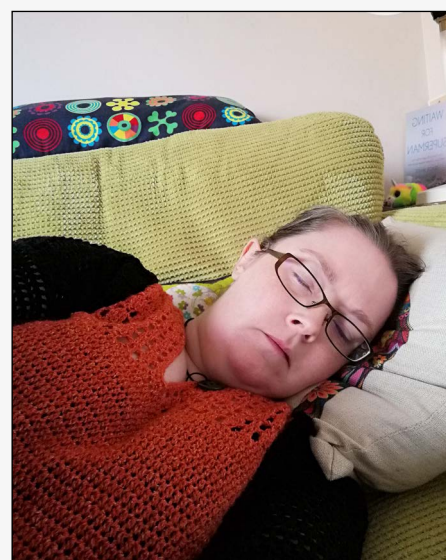
### a. How to start your claim for PIP

To begin your claim, you should read the information on the government website, check your eligibility, and then telephone the number provided:

**Gov.UK:** Personal Independence Payment: How to Claim:

<https://www.gov.uk/pip/how-to-claim>

You will then be sent a form titled, 'How your disability affects you' in the post. You need to fully complete this form and return it before any assessment can proceed. In the sections below, we take you through the form and provide some helpful tips and examples that might make completion easier and increase the chance of a correct award being made.



Remember that you do not have to be completely unable to carry out a task to score points.

### 3: IMPORTANT PRINCIPLE: 'RELIABLY'

PIP is assessed on the ability to complete activities which are described in various 'descriptor' statements (see example below). The more points you score, above the minimum required, across all descriptors the greater the monetary award.

ACTIVITY	DESCRIPTOR	POINT SCORE
<b>1. Preparing food.</b>	a. Can prepare and cook a simple meal unaided.	0
	b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.	2
	c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.	2
	d. Needs prompting to be able to either prepare or cook a simple meal.	2
	e. Needs supervision or assistance to either prepare or cook a simple meal.	4
	f. Cannot prepare and cook food.	8

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

While some people with ME/CFS will not be able to complete an activity, others might have found coping strategies and workarounds for their daily living requirements simply because they have no other choice.

While some people with ME/CFS might be able to initiate or even complete an activity, they may not be able to do it "reliably" – according to the definition of this term in the PIP legislation. This is vital to understand because while you may be able to initiate or complete an activity in the descriptor given the right circumstances, it doesn't mean that you can do so "reliably" and therefore that descriptor should not be applied to you and a more appropriate one selected.

### What does 'reliably' mean in PIP?

Regulation 4(2A) of the main PIP regulations provides:

"Where [a claimant's] ability to carry out an activity is assessed, [the claimant] is to be assessed as satisfying a descriptor only if [the claimant] can do so: (a) safely, (b) to an acceptable standard, (c) repeatedly, and (d) within a reasonable time period."

**Source:** <https://tinyurl.com/27evrnt>

Because ME/CFS can mean regular fluctuations in symptom severity and in functional ability, before answering "yes" or "no" to whether you can carry out a task on a daily basis, stop and think for a moment:

- Do you manage to complete the activity reliably?
- Do you need help to manage this activity?
- Do you have to modify how you manage this activity?

Bear in mind you do not have to be completely unable to carry out a task in order to score points. You score points when you cannot complete a task 'reliably'. In practice this means:

- **Safely:** in a manner unlikely to cause harm to you or to another person, either during or after completion of the activity.
- **Acceptable standard:** the task must be done to a standard that would reasonably be considered acceptable to most people.
- **Repeatedly:** as often as the activity being assessed is reasonably required to be completed.
- **Reasonable time period:** no more than twice as long as the maximum period that a person without your disability would normally take to complete that activity.



While you might be able to initiate or complete an activity given the right circumstances, it doesn't mean you won't attract points when your application is assessed.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

DWP guidance states that 'pain, fatigue, breathlessness, nausea and motivation' will all be key factors in deciding whether an activity can be carried out reliably.

If you struggle with tasks for part of a day, a descriptor should still apply for that day if the inability to perform a task is 'for a period which was more than trifling and has some degree of impact on a claimant's daily activity and functioning.'

**For Example:** if you can't dress yourself until late afternoon because of a symptom such as fatigue or pain, this should still be counted as a day in which you have difficulties for that activity, even though you may eventually manage to be dressed.

If your condition fluctuates daily, a descriptor will apply to reflect your ability for more than 50% of days. This is known as 'the majority of the time' rule. It will be considered over a 12-month period, looking back three months and forward nine months. If you have difficulty remembering how you have functioned and predicting how you will function, take a recent shorter period, and work it out from there.

A diary would give a picture of your condition over time. It might help you see how you qualify for points which are scored in various ways.

If you satisfy more than one descriptor over more than half the day, the descriptor that scores the highest number of points is the one that will be used, even if it is not the one that applies most often.

**For Example:** if you need an aid to wash yourself on 90% of days (two points) but on 55% of days you need help to get into the bath or shower (three points), you will score three points for the washing and bathing activity.

### a. What does this mean in practice?

You should answer each question as if the word 'reliably' was included in the question. This may mean that you answer "No" to some things that initially seem as though you can complete them.

For example, can you prepare and cook food reliably? You may be able to manage this activity but if you can't do it reliably, it has to be treated as though you can't complete it at all.



DWP guidance states that 'pain, fatigue, breathlessness, nausea and motivation' will all be key factors in deciding whether an activity can be carried out reliably.

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### CASE STUDY

Kelvin has ME/CFS but can cook his own food. The activity on the PIP form is called 'Preparing Food' and the descriptors are as follows:

- a. Can prepare and cook a simple meal unaided.
- b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal.
- c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave.
- d. Needs prompting to be able to either prepare or cook a simple meal.
- e. Needs supervision or assistance to either prepare or cook a simple meal.
- f. Cannot prepare and cook food.

He has multiple difficulties doing this activity as he gets fatigued and becomes dizzy very quickly when standing upright. He has pain in his fingers and arm when he grips a knife to put enough pressure on for chopping vegetables.

He has brain fog and loses track of what steps he has already taken. His brain fog also means he loses concentration, and he can burn things because he forgets to check on them. He has had a kitchen fire 6 months ago and the fire brigade had to attend.

He gets very fatigued after cooking because of the energy expended. This means he is unable to cook another meal when it is next needed as he is still recovering. These problems occur an average of 5 days a week depending on Kelvin's fluctuation of his symptoms and functional ability.

### Interpretation

Kelvin can cook his own food, but he cannot do it 'reliably' in this context. To decide which descriptor best fits his level of ability, we need to look at the problems he has that prevent him from 'reliably' completing this activity. What would enable him to prepare and cook his food to a reliable standard? An aid or appliance such as a perching stool to rest on may make enough of a difference to enable Kelvin to manage reliably. But if this does not address all of Kelvin's difficulties, he may qualify for a higher descriptor such as needing supervision to keep him safe and to prompt him on each step.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### b. PIP Assessment Guide from DWP

The PIP Assessment Guide from the DWP is issued to the healthcare professionals who complete medical assessments. It states:

“The fact that a claimant can complete an activity is not sufficient evidence of ability. HPs must consider:

■ **approach** – what the claimant needs to do; how they carry out the task; what assistance or aids are required; how long it takes; whether they can do it whenever they need to; and whether it is safe.

■ **outcome** – whether the activity can be successfully completed and the standard that is achieved.

■ **impact** – what the effect of reaching the outcome has on the claimant and, where relevant, others; and whether the claimant can repeat the activity within a reasonable period of time and to the same standard (this clearly includes consideration of symptoms such as pain, discomfort, breathlessness, fatigue, and anxiety). The impact of completing one activity on the ability to complete others must also be considered.

■ **variability** – how a claimant's approach and outcomes and level of functional restriction change over time and the impact this has on them.”

**Source: PIP Assessment Guide Part Two:** The Assessment Criteria 2.1.4:

<https://tinyurl.com/38jxwtd7>

This means it is also important to describe the effect completing an activity has on you afterwards. Does ‘Post-Exertional Malaise’ mean that you are unable to complete any other activities for a period of time afterwards? Are you dizzy or in pain, etc.?

The DWP assess ability to complete activities over time. Words and phrases like ‘sometimes’ or ‘a lot of the time’ are meaningless and will be ignored or not given adequate weighting.

Try to be as specific as possible, even when things do vary. If you keep an activity diary, use this to try to work out an average. Use specific and measurable times whenever possible. Relate this to any evidence you have.



### CASE STUDY

John does not get dressed an average of 4 days out of 7. This is demonstrated in his activity diary and referred to in his statement of needs by Adult Social Services. He is too fatigued to get dressed every day as it takes him at least half an hour to put clothes on. He cannot complete this reliably as it takes him more than twice as long as a healthy person would need to complete. John needs to rest throughout this activity in order to complete it and then requires a recovery period of an hour as a result of completing this activity.

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### 4: THE 'HOW YOUR DISABILITY AFFECTS YOU' FORM

#### Questions 1 & 2

These initial questions are about your healthcare professionals, health conditions, treatments, and medication. List all the healthcare professionals you see (including OTs and physiotherapists, etc.) or have seen, plus social workers, support and care workers, counsellors, and therapists, etc.

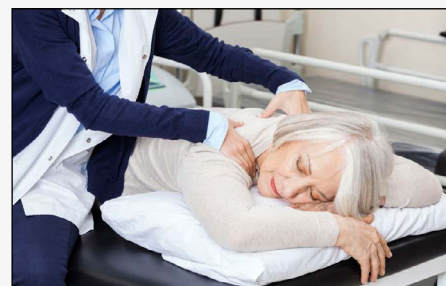
Note that Atos or Capita (the companies who complete the assessments for the DWP) will not necessarily contact everyone you list on the form. Try to get written evidence from these healthcare professionals yourself.

**Tip:** Do not delay sending off your claim because you are awaiting evidence. You can send in any evidence you receive separately at a later date.

List all your health conditions, physical and mental. In the section on medication, list all medicines and treatments you are currently taking or have been taking recently. The assessors may use this information to help work out the severity of your condition. If you are not on medication, or not on strong medication, because of side-effects or struggle with sensitivities, be sure to include these explanations or it may be wrongly assumed that you are not, for example, in serious pain.

If you have had treatment in the past that shows how serious your condition is, reveal it here – even if it might have been several years ago. For instance, you may have attended a pain clinic, been prescribed physiotherapy, or been fed by tube. If you were discharged from a service because they only offered a limited number of appointments, or felt that you could not progress any further, be sure to include this as well.

Mention any aids or appliances you use as you could gain extra points. An aid or appliance is defined as, (i) any device that improves, provides, or replaces your impaired physical or mental function, and (ii) includes a prosthesis. In other words, these include not only specialised disability aids, but also everyday ones like an electric tin-opener or food processor. Items that might more commonly be thought of as adaptations, such as a handrail, also count.



List all the healthcare professionals you see, including OTs and physiotherapists.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### SECTION 1: DAILY LIVING ACTIVITY QUESTIONS

Each of these questions has a series of tick boxes as well as a blank box to clarify answers. Use the blank boxes to give a full account of the difficulties you have with each of the scored activities.

**Tip:** Even if you can do an activity but can't do it 'reliably' then it is probably best to tick the 'No' box and describe the difficulties you have with it. For help understanding what 'reliably' means and why it is so important, please refer to the sections later in this guide.

There is not a lot of space on the paper form, and it is absolutely acceptable to write, "Please see attached sheet" and then write your answers up on a separate piece of paper. Just make sure that you put your name and national insurance number at the top of every sheet to ensure that it is included in your claim.

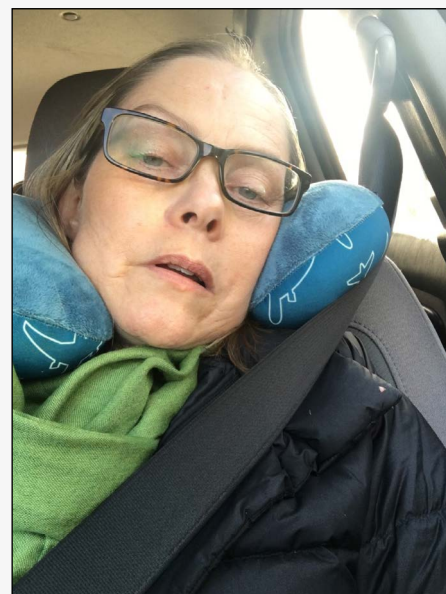
**Tip:** This means that if you struggle to handwrite but can type or use voice recognition software then you can use your computer to help you and print the information afterwards.

The questions on the form relate to the activities that the DWP use to work out how many points to award you, but they do not mention each of the descriptors or the corresponding points. Because of this, it is really useful for you to know the descriptors they are assessing you against before you answer each question.

We have included the descriptors for each activity below, with some examples of how they may relate to symptoms of ME/CFS. We suggest you go through them slowly and tackle one activity at a time by using the SCORE YOURSELF boxes we have supplied and complete the prompts about how you do or don't manage each activity.

#### Before you begin the form:

- Try to look at your symptoms with fresh eyes. It's easy to forget how ME/CFS affects your ability to do things when you live with it every day!
- Make a list of all of the symptoms and when they occur.
- Some symptoms are present every day, some will only occur when you complete a particular activity, and some will be variable.



Try to look at your symptoms with fresh eyes. It's easy to forget how ME/CFS affects your ability to do things when you live with it every day.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

■ Consider when they are at their worst and which symptoms affect each activity.

### Ask yourself:

How do the symptoms contribute to the difficulty of trying to complete an everyday activity? How do they affect my behaviour and my day-to-day life? Does an activity cause certain symptoms to increase afterwards? How long do I take to recover after an activity?

### Question 3. Daily Living Activity 1:

#### PREPARING FOOD

Remember your list of symptoms. Have a look at which of these apply to this activity. This question is specifically about your ability to prepare a cooked, one-course meal for one person using fresh ingredients.

Some of the definitions used by the DWP are not the standard definitions most of us would assume. For example, 'to cook' means "to heat food at or above waist height" which immediately discounts any difficulties someone may have with bending down to put things in or take things out of an oven.

DWP guidance also states, "pre-chopped vegetables are not considered an aid or appliance. However, a claimant who is reliant on them because they would be unable to peel or chop fresh vegetables may be considered as requiring an aid or appliance or support from another person to complete the activity".

Decision-makers may argue that you could and should use an aid or appliance as an alternative to having supervision or assistance from another person. Be prepared to explain why the aid or appliance would not mitigate your need for help.

**Tip:** timers might not help because you would forget to set them or get confused about why they were going off. A perching stool might not help because you have dizzy spells and might fall off, etc.

If you cook food even though it is dangerous for you to do so, or it often goes wrong because you don't have the ability or the help you would need, then explain what can happen when you attempt this activity. Remember to be specific about how often this can happen.

SYMPTOM	TICK
Anxiety	
Brain fog	
Breathlessness	
Concentration problems	
Cramps and muscle spasms	
Depression	
Difficulty staying awake	
Dizziness	
Exhaustion/Fatigue/Lack of energy, etc.	
Insomnia	
Irritable Bowel Syndrome or gastrointestinal difficulties	
Memory problems	
Muscle weakness	
Muscle tiredness	
Nausea	
Orthostatic intolerance	
Pain – muscular, skeletal, headaches, migraines	
Peripheral neuropathy	
Post-Exertional Malaise	
Sensitivity to stimulation e.g., light/sound/touch/chemicals	
Sleep disturbances	
Unrefreshing sleep	





## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### Score yourself

#### Activity 1: Preparing Food.

##### Descriptors:

- Can prepare and cook a simple meal unaided (0 points).
  - Needs to use an aid or appliance to be able to either prepare or cook a simple meal (2 points).
  - Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave (2 points).
  - Needs prompting to be able to either prepare or cook a simple meal (2 points).
  - Needs supervision or assistance to either prepare or cook a simple meal (4 points).
  - Cannot prepare and cook food (8 points).
- 
- Which descriptors apply the majority of the time?
  - How often do they apply?
  - What symptoms cause me to have difficulties?
  - What aids or appliances do I use?
  - What help do I receive?
  - Am I 'reliably' able to complete this activity?
  - What evidence or examples of these problems can I provide?
  - Do I suffer from any difficulties after this activity?



#### MY NOTES:

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# PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

## Question 4. Daily Living Activity 2:

### EATING AND DRINKING

You may have to think about whether you need to be prompted, reminded, or motivated, to eat. Perhaps you often feel too ill to eat or too exhausted to bother.

Some people with severe or very severe ME/CFS require tube-feeding and if this applies to you then you should describe the process and the help that you need.

If you use any aids or adaptations to help you eat or drink, mention them in this section even if you have previously described them when answering Question 3.

### Score yourself

#### Activity 2: Taking Nutrition.

##### Descriptors:

- a. Can take nutrition unaided (0 points).
  - b. Needs:
    - (i) to use an aid or appliance to be able to take nutrition, or
    - (ii) supervision to be able to take nutrition, or
    - (iii) assistance to be able to cut up food (2 points).
  - c. Needs a therapeutic source to be able to take nutrition (2 points).
  - d. Needs prompting to be able to take nutrition (4 points).
  - e. Needs assistance to be able to manage a therapeutic source to take nutrition (6 points).
  - f. Cannot convey food and drink to their mouth and needs another person to do so (10 points).
- Which descriptors apply the majority of the time?
  - How often do they apply?
  - What symptoms cause me to have difficulties?
  - What aids or appliances do I use?
  - What help do I receive?
  - Am I 'reliably' able to complete this activity?
  - What evidence or examples of these problems can I provide?
  - Do I suffer from any difficulties after this activity?

### CASE STUDY

Margot suffers from extreme fatigue, brain fog/memory problems, nausea, sensitivity to smells, and lack of appetite as symptoms of her ME/CFS.

These occur every day and mean that she is disinterested in food, forgets to eat, finds food makes her feel more ill and makes eating physically tiring.

If she is not prompted by her carer, then she would not eat reliably every day. Margot has lost 7kg in the last 12 months and is now slightly underweight. She has been referred to a community dietician by her GP.

### MY NOTES:

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**PERSONAL INDEPENDENCE PAYMENT  
A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS**

**Question 5. Daily Living Activity 3:**

**MANAGING TREATMENTS**

This activity considers your ability to monitor your health, your medication and cope with treatments. You may not be able to consistently take medication without help or someone to remind you.

Do you need help opening blister packs or someone to fill up a 'Dosette Box' with your medications? Your ability to monitor and detect changes in your health may also require assistance and objective input from a helper. Perhaps you need help with any form of activity management you have been prescribed.

Be clear if your GP, OT, physiotherapist or ME/CFS Specialist Service has asked you to carry out an activity, or to keep a diary, and you require daily prompting or even physical assistance. You may find it very difficult to practice 'pacing' without help because of the severity of your symptoms.

Describe why you need help and what happens if you do not get that help.

**Score yourself**

**Activity 3: Managing therapy or monitoring a health condition.**

**Descriptors:**

- a. Either –
  - (i) does not receive medication or therapy or need to monitor a health condition; or
  - (ii) can manage medication or therapy or monitor a health condition unaided (0 points).
- b. Needs either –
  - (i) to use an aid or appliance to be able to manage medication; or
  - (ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition (1 point).
- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week (2 points).
- d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week (4 points).

**MY NOTES:**

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week (6 points).

f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week (8 points).

- Which descriptors apply the majority of the time?
- How often do they apply?
- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?

### CASE STUDY

Paul forgets to take his medication when he should due to his poor memory. He has previously tried to set phone alarms to remind him but, as he has to sleep throughout the day, the alarms didn't help.

If he doesn't take his medications on time and in the correct daily dose, then the medications lose their efficacy. He has forgotten that he already took his medicine and accidentally double-dosed himself on multiple occasions and has frequently missed doses.

Because of this he cannot reliably take his medicine and needs prompting and supervision to ensure he takes the correct dose at the correct time.



### MY NOTES:

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PERSONAL INDEPENDENCE PAYMENT  
A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

Question 6. Daily Living Activity 4:

WASHING AND BATHING

If you often neglect personal hygiene e.g., regularly washing, bathing, or showering because your symptoms are so severe or they make these activities difficult or impossible, then say so.

Outline any problems you have washing yourself, including difficulty gripping, reaching parts of your body, if you rely on someone else or on aids or appliances to help. If bathing or showering are potentially dangerous – as a result of orthostatic intolerance or muscle weakness for example, and the possibility that you will faint or collapse or be unable to get out of the bath, etc. – then make this clear in your answer.

Score yourself

Activity 4: Washing and Bathing.

Descriptors:

- a. Can wash and bathe unaided (0 points).
- b. Needs to use an aid or appliance to be able to wash or bathe (2 points).
- c. Needs supervision or prompting to be able to wash or bathe (2 points).
- d. Needs assistance to be able to wash either their hair or body below the waist (2 points).
- e. Needs assistance to be able to get in or out of a bath or shower (3 points).
- f. Needs assistance to be able to wash their body between the shoulders and waist (4 points).
- g. Cannot wash and bathe at all and needs another person to wash their entire body (8 points).

- Which descriptors apply the majority of the time?
- How often do they apply?
- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?

MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### CASE STUDY

Stewart only manages to wash parts of his body an average of twice a week. He would like to wash at least once a day as he struggles to regulate his body temperature and finds that he sweats excessively.

The process of getting in and out of the bath, of attempting to wash, and the stimulation caused by warm water added significantly to his exhaustion. He gets dizzy when standing up out of a bath (or in a shower) and has previously fallen several times hurting himself and making him very anxious about his safety (please see attached evidence of a discharge notice from A&E after he required medical attention after falling). This experience led to him avoiding baths and showers (his shower is above the bath).

Stewart needs prompting to wash himself. When he does attempt a full-body wash, he can only manage to wash small parts of his body at each attempt and uses 'bed-bath wipes' to help. He suffers from acute pain in his shoulders and neck and weakness in his arms, so he has to proceed



slowly and cannot reach all areas. Washing his hair represents a significant challenge and one he only attempts once every four weeks on average with help from a friend who occasionally visits him at home.

Stewart has to lie down and rest after each attempt at washing because it exacerbates his symptoms, and he is exhausted by the process. This means he is unable to complete any further activities for several hours.

# PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### Question 7. Daily Living Activity 5:

#### MANAGING TOILET NEEDS

This relates to your ability to get on or off the toilet and to clean yourself afterwards, which is a fairly common cause of injuries. Do not be bashful if you struggle with this activity. It is an important part of daily life and psychological well-being.

Getting to and from the toilet is not considered part of this activity but getting on and off the toilet is. If you feel weak or faint, struggle with exhaustion or pain, you may need help. Do you use handrails, an adaptation to the toilet seat, or even a sink to help raise and lower yourself from the toilet?

Remember, aids and adaptations can include everyday items as well as those designed for disabled people if you are using them to help you with an activity.

#### Score yourself

##### Activity 5: Managing Toilet Needs or Incontinence.

##### Descriptors:

- a. Can manage toilet needs or incontinence unaided (0 points).
- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence (2 points).
- c. Needs supervision or prompting to be able to manage toilet needs (2 points).
- d. Needs assistance to be able to manage toilet needs (4 points).
- e. Needs assistance to be able to manage incontinence of either bladder or bowel (6 points).
- f. Needs assistance to be able to manage incontinence of both bladder and bowel (8 points).
- g. Cannot wash and bathe at all and needs another person to wash their entire body (8 points).

- Which descriptors apply the majority of the time?
- How often do they apply?
- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?

#### MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### CASE STUDY

Susan does not have solid bowel movements. She suffers from diarrhoea which can occur at any time but often shortly after eating. She gets stomach pain and not much warning before she needs to use the toilet an average of 4 times a day. She is not always able to get to the toilet and soils herself an average of 4 times a week.

Because Susan is in pain, fatigued, and experiences muscle weakness, she uses the sink to help lower herself on and off the toilet. She wears disposable 'adult nappies' and finds soiling herself to be very distressing.

It takes her an average of 15 minutes to clean herself with 'wet wipes', dispose of the nappy, replace it with a fresh one, and attempt to clean the toilet afterwards.

Susan is exhausted and anxious following each visit to the toilet and will need to rest. She cannot attempt another activity for at least an hour afterwards.



Are you able to use the toilet without help?  
Does this activity leave you anxious and exhausted afterwards?



PERSONAL INDEPENDENCE PAYMENT
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Question 8. Daily Living Activity 6:

DRESSING AND UNDESSING

If you do not dress or undress very often because of exhaustion, depression, or feeling too ill, etc. then say so here. Outline any problems you experience when trying to dress yourself, perhaps with dizziness, fainting, grip, muscle weakness or pains that make reaching, stretching, or bending difficult.

Perhaps you don't get the help you need to do this activity as often as you would like, or you have to choose clothing that can be pulled on easily or fastened with Velcro rather than with buttons or zips. Perhaps you often stay in your nightclothes to conserve energy or because dressing aggravates your symptoms.

Are you sensitive to constricting waistbands or certain fibres? If you do manage to dress yourself, how long does this take you? Time yourself. Is it easier to get dressed, or to get undressed? Why?

Score yourself

Activity 6: Dressing and Undressing.

Descriptors:

- a. Can dress and undress unaided (0 points).
b. Needs to use an aid or appliance to be able to dress or undress (2 points).
c. Needs either -
(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
(ii) prompting or assistance to be able to select appropriate clothing (2 points).
d. Needs assistance to be able to dress or undress their lower body. (2 points)
e. Needs assistance to be able to dress or undress their upper body. (4 points)
f. Cannot dress or undress at all. (8 points)
■ Which descriptors apply the majority of the time?
■ How often do they apply?
■ What symptoms cause me to have difficulties?
■ What aids or appliances do I use?

MY NOTES:

Horizontal lines for taking notes.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?

### CASE STUDY

Morris gets dressed twice a week when he is taken out by his support worker. The rest of the time he does not get dressed and stays in the same night clothes.

Morris often lacks the ability and motivation to get dressed or to change into clean pyjamas. He is fatigued every day and has to choose which activities he can manage with his limited energy.

It takes Morris at least 30 minutes to change pyjamas as he finds it very tiring, and it causes him a great deal of pain. If he is going outside, then he has help from his support worker who will select appropriate clothing and help him get dressed.

Bending down to pull trousers over his legs makes him dizzy. He has pain in his muscles and struggles to grip properly with his hands. He can't manage buttons or laces and uses draw-string trousers and slip-on shoes with a 'long-handled shoehorn'. He cannot put socks on by himself even with an appropriate disability aid.

Morris has had to go to the GP for an appointment (when he couldn't get a home visit) in his dirty pyjamas without socks and in his slippers as he was too unwell to get changed.



If you do not dress or undress very often because of exhaustion, depression, or feeling too ill, etc., say so.

PERSONAL INDEPENDENCE PAYMENT  
A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

**Question 9. Daily Living Activity 7:**

**COMMUNICATING**

This activity is about understanding others and making yourself understood. It is mainly aimed at people who have cognitive difficulties such as learning disabilities and the bar to achieve points for this activity is set quite high.

**For Example:** “complex verbal information” is defined as “information in your native language conveyed verbally in either more than one sentence or one complicated sentence,” which can mean that even fairly simple conversations can be counted as complex verbal information.

Talking and listening can also have an effect on your mental health by taxing your confidence. You might feel exhausted after conversations or as a result of having to absorb information and need time or aids to process it.

**Cognitive dysfunction** – problems with concentration and attention span, short-term memory, and information processing – is an important and sometimes very disabling symptom of ME/CFS.

Perhaps you have to schedule and limit the length of conversations because you find them so draining. You may only be able to communicate effectively in the morning and need to rest afterwards. There might be times when you are simply too unwell to communicate. Perhaps you put off phone calls and have to postpone appointments or need to communicate in writing rather than verbally.

Bear in mind that the definition of ‘complex verbal information’ means that a lot of people with ME/CFS may not score points for this activity.

**Score yourself**

**Activity 7: Communicating Verbally.**

**Descriptors:**

- a. Can express and understand verbal information unaided (0 points).
- b. Needs to use an aid or appliance to be able to speak or hear (2 points).
- c. Needs communication support to be able to express or understand complex verbal information (4 points).

**MY NOTES:**

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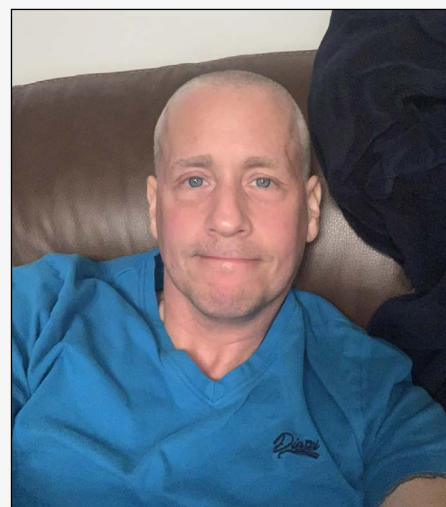


## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

d. Needs communication support to be able to express or understand basic verbal information (8 points).

e. Cannot express or understand verbal information at all even with communication support (12 points)

- Which descriptors apply the majority of the time?
- How often do they apply?
- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?



Talking and listening can have an effect on your mental health by taxing your confidence. You might feel exhausted after conversations or as a result of having to absorb information.

# PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

## Question 10. Daily Living Activity 8:

### READING

This activity is mainly aimed at people who have cognitive difficulties such as learning disabilities and the bar to achieve points is set quite high.

**For Example:** "complex written information" means "more than one sentence of written or printed standard-size text in your native language," so if you can read this paragraph then you can read complex written information!

Highly relevant for people with ME/CFS is the ability to understand written information. As a result of your illness, you may have problems reading and processing information – something that you never experienced before.

You may need help from someone else to understand and complete basic forms and routine paperwork. Perhaps you struggle to read, have to use text-to-speech software or even rely on audio books for reading novels in short sessions.

Bear in mind that the definition of 'complex written information' means that a lot of people with ME/CFS may not score points for this activity.

### Score yourself

#### Activity 8: Reading and understanding signs, symbols, and words.

#### Descriptors:

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses (0 points).
- b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information (2 points).
- c. Needs prompting to be able to read or understand complex written information (2 points).
- d. Needs prompting to be able to read or understand basic written information (4 points).
- e. Cannot read or understand signs, symbols, or words at all (8 points).

- Which descriptors apply the majority of the time?
- How often do they apply?

### MY NOTES:

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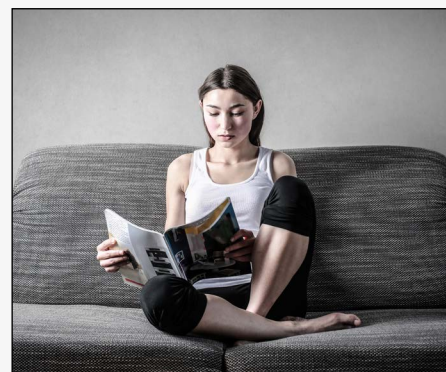
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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?



“Complex written information” means “more than one sentence of written or printed standard-size text in your native language,” so if you can read this paragraph then you can read complex written information!

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### Question 11. Daily Living Activity 9:

#### MIXING WITH OTHER PEOPLE

You may want to describe how extreme exhaustion and/or poor concentration means you have difficulty following what people say and difficulty responding appropriately. Further, this may diminish your confidence and lead to social anxiety whereby you simply avoid people. Perhaps you can only engage socially for brief periods but cannot do so 'reliably and repeatedly' or your symptoms relating to noise sensitivities and stimulation are so severe that you are unable to engage socially at all or verbally converse with others.

#### Score yourself

##### Activity 9: Engaging with other people face to face.

##### Descriptors:

- a. Can engage with other people unaided (0 points).
  - b. Needs prompting to be able to engage with other people (2 points).
  - c. Needs social support to be able to engage with other people (4 points).
  - d. Cannot engage with other people due to such engagement causing either –
    - (i) overwhelming psychological distress to the claimant; or,
    - (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person (8 points).
- Which descriptors apply the majority of the time?
  - How often do they apply?
  - What symptoms cause me to have difficulties?
  - What aids or appliances do I use?
  - What help do I receive?
  - Am I 'reliably' able to complete this activity?
  - What evidence or examples of these problems can I provide?
  - Do I suffer from any difficulties after this activity?

#### CASE STUDY

Ahmed is very sensitive to noise and becomes overstimulated in company. He gets exhausted very quickly when concentrating and listening to a conversation and has problems articulating coherent replies. This has affected his confidence and led to anxiety and distress in social situations and to panic attacks.

He now avoids conversations with other people, and he can only reliably manage interactions if he limits the contact, has support from his partner – who provides reassurance and can assist with interpretation and prompting when needed. Ahmed is prescribed Sertraline for his anxiety by his GP.

#### MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### Question 12. Daily Living Activity 10:

#### MAKING DECISIONS ABOUT MONEY

It is not uncommon for people with ME/CFS to need help sorting their finances. Brain fog and other cognitive challenges can mean that you are not as able in this area as you were before your illness and need to depend on the help of someone else or maybe it takes you longer to manage your finances and make monetary decisions because you are easily confused.

Perhaps you struggle to concentrate or become easily overwhelmed and cannot make sensible decisions? Maybe you are too exhausted and ill to deal with budgets and the stress of bills?

Do you forget to pay bills or make mistakes and pay the wrong amount? If you do manage to go out to the shops, can you handle paying for purchases? Can you establish and maintain a monthly budget or is this too much of a challenge?

#### Score yourself

##### Activity 10: Making Budgeting Decisions.

##### Descriptors:

- a. Can manage complex budgeting decisions unaided (0 points).
  - b. Needs prompting or assistance to be able to make complex budgeting decisions (2 points).
  - c. Needs prompting or assistance to be able to make simple budgeting decisions (4 points).
  - d. Cannot make any budgeting decisions at all (6 points).
- Which descriptors apply the majority of the time?
  - How often do they apply?
  - What symptoms cause me to have difficulties?
  - What aids or appliances do I use?
  - What help do I receive?
  - Am I 'reliably' able to complete this activity?
  - What evidence or examples of these problems can I provide?
  - Do I suffer from any difficulties after this activity?

#### MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### SECTION 2: MOBILITY ACTIVITY QUESTIONS

#### Question 13. Mobility Activity 1:

##### PLANNING AND FOLLOWING A JOURNEY

This concerns your ability to plan and follow a journey that is either familiar or unfamiliar to you. People with ME/CFS might struggle to score points here unless they are prone to anxiety or panic attacks. However, some describe cognitive difficulties with planning and making journeys and then feeling disoriented and confused when they try, so do check the descriptors and definitions carefully to see if you can meet the criteria.

Are you physically or emotionally able to plan and make a journey outside of your home? Can you do so 'safely, reliably, and repeatedly'? Do you need someone else to plan a journey and accompany you when making the trip?

Explain why you need help and what happens if you experience anxiety or are prone to panic attacks. You might get overwhelmed by your sensitivity to noise and light and become disorientated or have needed to cut journeys short perhaps resulting in cancelled appointments when your symptoms are at their worst.

##### Score yourself

##### Mobility Activity 1: Planning and following journeys.

##### Descriptors:

- Can plan and follow the route of a journey unaided (0 points).
- Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant (4 points).
- Cannot plan the route of a journey (8 points).
- Cannot follow the route of an unfamiliar journey without another person, assistance dog, or orientation aid (10 points).
- Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant (10 points).
- Cannot follow the route of a familiar journey without another person, an assistance dog, or an orientation aid (12 points).

- Which descriptors apply the majority of the time?
- How often do they apply?



Are you able to plan  
and make a journey  
outside of your home?  
Or do you need  
someone else to plan  
and accompany you  
when you make the  
trip?



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

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- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?



# PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

## Question 14. Mobility Activity 2:

### MOVING AROUND

The DWP dictates that this activity should be judged in relation to the type of surface expected outdoors, including obstacles such as kerbs. When considering the descriptors, always think about the key issues involving 'safely, reliably, and repeatedly' and whether you can walk the distance at all or in a 'reasonable period of time'.

For example, if you can walk 20 to 50 metres but only with discomfort and you cannot do so reliably or repeatedly then indicate that you can walk 'less than 20 metres', or '20-50 metres' as appropriate. Explain in more detail about the problems you have walking in the information section.

State how far you can walk before you experience pain, severe discomfort, fatigue, breathlessness, muscle weakness, etc. You should also make it clear when you cannot walk either at all or 'repeatedly and reliably' because the severity of your symptoms and the physical impact they have on your walking ability mean there are times when you are housebound or bedbound.

It is worth considering whether there are any aids that would help you to walk as the DWP may argue that you could use them. For example, a walking stick may help with balance problems but would not reduce exhaustion and fatigue. It may be that it is not possible to use a stick due to pains in the hands or arms or owing to muscle weakness or an enfeebled grip. If you do use an aid, then it will not rule out scoring points but think carefully about what you want to say.

### Score yourself

#### Mobility Activity 2: Moving Around.

#### Descriptors:

- a. Can stand and then move more than 200 metres, either aided or unaided (0 points).
- b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided (4 points).
- c. Can stand and then move unaided more than 20 metres but no more than 50 metres (8 points).
- d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres (10 points).
- e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided (12 points).

#### MY NOTES:

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## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

f. Cannot, either aided or unaided, –

(i) stand; or

(ii) move more than 1 metre (12 points).

- Which descriptors apply the majority of the time?
- How often do they apply?
- What symptoms cause me to have difficulties?
- What aids or appliances do I use?
- What help do I receive?
- Am I 'reliably' able to complete this activity?
- What evidence or examples of these problems can I provide?
- Do I suffer from any difficulties after this activity?

### CASE STUDY

Jing Mei is housebound an average of 6 days a week. On these days she will manage to slowly walk around her house with extensive rest periods in-between. She cannot repeatedly walk more than 20m as she is greatly affected by the severity of her symptoms, but she manages to walk outside an average of 1 day a week.

### CASE STUDY

Tobias cannot stand without support from someone else and only for a very limited time to help him move from one place to another within his home - for example from his bed to a bedroom chair. He cannot walk and is wholly reliant on a wheelchair that he is helped into and out of and which he uses mainly about the house and in the garden for short durations. He can use the wheelchair if he needs to attend medical appointments or to take organised trips but only with the assistance of his support worker. He is unable to drive himself and relies on an adapted Motability vehicle.



A walking stick may help with balance problems but would not reduce exhaustion and fatigue.

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### Question 15. Additional information.

Add any relevant information not included elsewhere and recap important points. Give some background information about your condition (but focus on how it affects you and not on the condition itself) and paint a general picture of how it restricts you. Perhaps you could briefly say how your life has changed and the independence you have had to give up since becoming ill with ME/CFS.

■ Remember, if you run out of space it is absolutely fine to add additional sheets with your name and national insurance number as a reference at the top of each page.

When you have completed the form and signed the declaration, remember to make a photocopy (or ask someone else to do it for you) of every page including any additional pages and supporting evidence before submitting it.

■ Keep the original copies of any medical and other supporting evidence – you would be surprised at how many times these forms get lost in the post or mislaid after they have reached their destination.

### IS A MEDICAL ASSESSMENT INEVITABLE?

If your claim is supported by strong evidence from healthcare professionals, such as doctors or social workers which satisfactorily address your ability to complete the Daily Living and Mobility activities, the assessment may be done 'on paper' without you having to attend an actual assessment interview.

Following the Covid-19 pandemic, face-to-face assessments have resumed but you might receive an assessment by phone or video, or you can request one if this is a better alternative. If you are likely to have difficulties travelling to attend a face-to-face medical, or if travelling and then participating in the interview would make your symptoms worse, then say so on the form.

The DWP, Atos, and Capita are public-service providers and duty-bound to make 'reasonable adjustments' for disabled people under the Equality Act 2010. Such adjustments might include:

- changing the appointment date because of illness severity fluctuations, or,
- requesting the assessment be done over several appointments to give you time to rest and recover, or,



Perhaps you could briefly say how your life has changed and the independence you have had to give up since becoming ill with ME/CFS.

The MEA has a free-to-download template letter available, **Disability Aids, Adaptations & Social Care**. This letter provides supporting evidence for the provision of disability aids such as wheelchairs, home adaptations and appliances for people with ME/CFS. It can also be used to help obtain aid from social care services:

<https://meassociation.org.uk/u1d8>



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

- requesting a telephone or video interview or home visit because you are too disabled or ill to leave your home or bed even with assistance, or,
- needing someone to attend the interview with you to remind or prompt or help you answer the questions, or to keep notes, or for reassurance and support.

Bear in mind that the information provided on the claim form must support your need for the reasonable adjustments to be made.

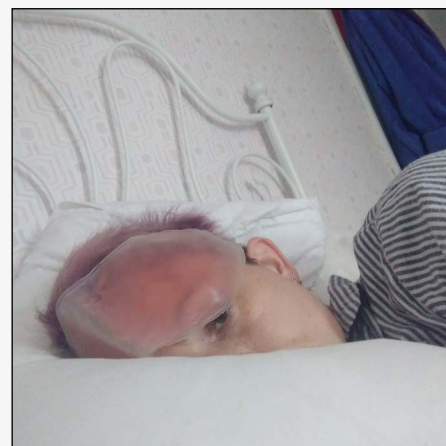
If you are unable to travel for a medical assessment, then inform Atos or Capita (the companies who complete the assessments on behalf of the DWP) when you receive the letter inviting you to attend. Where possible, home visits can be arranged, but there are no guarantees, and a telephone or video interview might be offered as an alternative where possible.

### More information

- DWP PIP Assessment Guide: Part 1 The Assessment Process | April 2022:

<https://tinyurl.com/ycxjnvwd>

Note: section 1.3.6 mentions reasonable adjustment considerations.



I usually wake with a severe headache, my muscles need time to work, I need assistance to get out of bed, and I have to take medication.

## WHAT HAPPENS AT A MEDICAL ASSESSMENT?

The medical assessment is another opportunity to gather evidence about which descriptors for each activity apply to you. It should feel very familiar as you will be asked similar questions to the ones you answered on the 'How Your Disability Affects You' form and the same principles apply.

When answering questions in the interview, you need to stress how 'reliably' you can complete an activity and be as specific as you can about how often this applies, just as you did when filling in the SCORE YOURSELF sections in this guide.

### For example:

- When asked about your ability to get out of bed you might not want to say, "Yes, I get up every day." Instead, you could say, "I can't get up until about 30 minutes after I wake because I am often distressed by an average of 4 hours disturbed sleep. I usually wake with a severe headache, my muscles need time to work, I need assistance to get out of bed, and I have to take medication."

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

■ When asked about your ability to prepare a simple meal, you shouldn't automatically say, "Yes, I can cook for myself," if it is more realistic to say, "On most days I am too exhausted and confused to prepare anything and my meals usually comprise a bowl of cereal or a sandwich that my partner has prepared for me."

The healthcare professional who completes the assessment is supposed to have read everything in your file before starting the interview. They should take a clinical history, noting your health conditions, how long you have had them and what treatments and medications you have tried.

### You should be asked about:

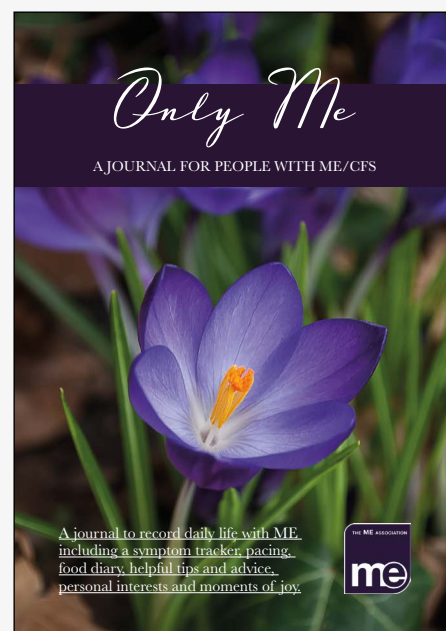
- where you live, your home-life, employment status (and what 'reasonable adjustments' are in place if you are able to work), and any social activities you engage in (or have had to give up),
- how your limitations affect your ability to perform everyday tasks and how mobile you are,
- a typical day in your life (when answering, explain your difficulties in full – with fluctuating conditions like ME/CFS, it is important that variations in symptom severity and functional ability are considered).
- good and bad days and how many of each you have (make it clear, if this is the case, that your 'good' days are better days, but are not good by normal peoples' standards).

Healthcare professionals are warned that a 'snapshot' of your condition on a particular day, or during the interview, is not adequate and that they need to consider your condition over time. Using an activity and symptom diary can be a good way of conveying your limitations and how they might vary over time.

You will be observed throughout the appointment on an informal basis, including when walking to and from the waiting room and recognising your name when it is called out. During the interview your hearing ability, your ability to mobilise, how you stand, sit, and move around (including tasks like picking up a handbag from the floor), your ability to concentrate and interact, will all be considered. You might have a brief physical examination, checking things like your eyesight, your blood pressure, your muscles, and the range of movement in your limbs.

The healthcare professional will make a note of your appearance. This will be used to draw conclusions about how able you are to take care of yourself. If you had help in dressing, washing, or even putting on make-up or nail varnish, then you should make this clear – as otherwise they may draw an inaccurate conclusion about your limitations.

Using an activity and symptom diary can be a good way of conveying your limitations and how they might vary over time.



The MEA has produced **Only Me**, a journal for people with ME/CFS to track symptoms, medication, appointments, pacing, food diary and to record how you feel. It also features enjoyable activity ideas, tips, advice – and so much more. It is undated, so you can use it at any time!

<https://meassociation.org.uk/8wh8>



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### RECEIVING THE DECISION

The case manager at the DWP will look at all the evidence you have submitted and from the medical assessment (if you have had one) to decide if you meet the criteria for an award.

You will receive a letter informing you of their initial decision. There is no set timeframe on how long this takes as it is dependent on how busy the DWP are which is very busy in light of the Covid-19 pandemic.

Please do not be disheartened if you receive a disappointing decision. The DWP are currently looking at reforming their decision-making process to try to make better decisions the first time round but as it stands, around 60% of decisions are turned down on first application.

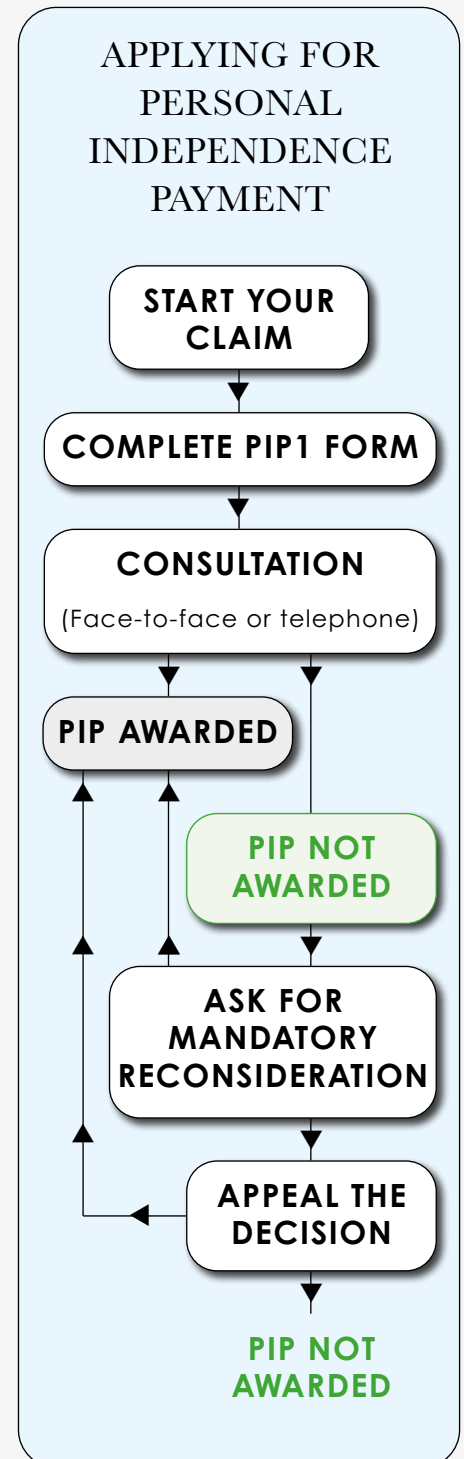
This does not mean that you do not deserve PIP. Seek advice from one of the recommended welfare rights services such as Citizens Advice or Disability Rights UK. You could also review the ME Association guide to mandatory reconsiderations and appeals for people with ME/CFS.

It is important to note that sometimes, despite having genuine disabilities, people simply do not fit into the strict criteria that are used to assess PIP. This is not a reflection on you although we of course recognise such a decision will be upsetting.

If you are not happy with the decision you have the right to request that the DWP reconsiders it. This is called a Mandatory Reconsideration and you must request this within one month of the initial decision being made.

If you are still not happy after this review has been completed, you may appeal to the Tribunals Service, which is an independent panel who will look at the DWP's decision and weigh it up against the evidence provided to decide what your award should be.

Currently around 70% of cases which proceed to Tribunal are decided in the claimant's favour. So, while it might sound like a scary and complicated process to endure, it could be worth your while considering.





## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### DWP TERMINOLOGY FOR PIP

The definitions used by the Department for Work and Pensions (DWP) when using terms that relate to disability and PIP do not always have the same meaning that the average person would give to them. These definitions are strictly defined in the legislation. To avoid confusion, it is important that you understand how the DWP uses these definitions.

**Aided with:** (a) the use of an aid or appliance, or (b) supervision, prompting or assistance.

**Aid or appliance:** (a) any device which improves, provides, or replaces your impaired physical or mental function, and (b) includes a prosthesis.

**Assistance:** physical intervention by another person not including speech.

**Assistance dog:** a dog trained to guide or assist a person with a sensory impairment.

**Basic verbal information:** information in your native language conveyed verbally in a simple sentence.

**Basic written information:** signs, symbols and dates written or printed standard-size text in your native language.

**Bathe:** includes getting into or out of an unadapted bath or shower.

**Communication support:** support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice-versa.

**Complex budgeting decisions:** decisions involving, (a) calculating household and personal budgets, (b) managing and paying bills, and (c) planning future purchases.

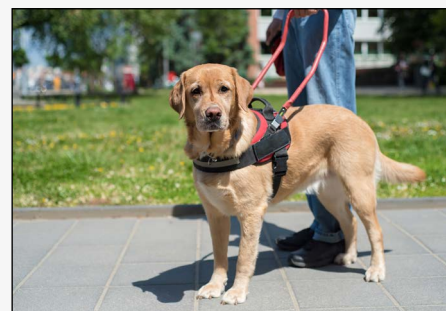
**Complex verbal information:** information in your native language conveyed verbally in either more than one sentence or one complicated sentence.

**Complex written information:** more than one sentence of written or printed standard-size text in your native language.

**Cook:** heat food at or above waist height

**Dress and undress:** including putting on and taking off socks and shoes.

**Engage socially:** (a) interact with others in a contextually and socially appropriate manner, and (b) understand body language, and (c) establish relationships.



**Assistance dog:** a dog trained to guide or assist a person with a sensory impairment.



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

**Manage incontinence:** Manage involuntary evacuation of the bowel or bladder, including using a collecting device or self-catheterisation, and cleaning yourself afterwards.

**Manage medication or therapy:** take medication or undertake therapy, where a failure to do so is likely to result in a deterioration in your health.

**Medication:** medication to be taken at home, which is prescribed or recommended by a registered, (a) doctor, or (b) nurse, or (c) pharmacist.

**Monitor health:** (a) being able to detect significant changes in your health condition which are likely to lead to a deterioration in your health, and (b) taking action that has been advised by a, (i) registered doctor, or (ii) registered nurse, or (iii) health professional who is regulated by the Health Professions Council without which your health is likely to deteriorate.

**Orientation aid:** a specialist aid designed to assist disabled people to follow a route safely.

**Prepare:** in the context of food, make food ready for cooking or eating.

**Prompting:** reminding, encouraging, or explaining by another person.

**Psychological distress:** distress related to an enduring mental health condition or an intellectual or cognitive impairment.

**Read:** includes read signs, symbols and words but does not include read Braille.

**Simple budgeting decisions:** decisions involving, (a) calculating the cost of goods, and (b) calculating change required after a purchase.

**Simple meal:** a cooked one-course meal for one using fresh ingredients.

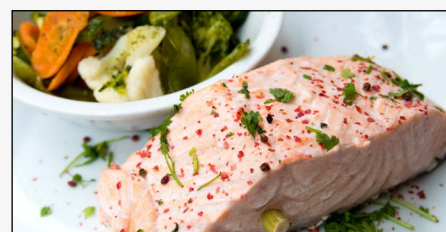
**Social support:** support from a person trained or experienced in assisting people to engage in social situations.

**Stand:** stand upright with at least one biological foot on the ground.

**Supervision:** the continuous presence of another person for the purpose of ensuring your safety.

**Take nutrition:** (a) cut food into pieces, convey food and drink to your mouth and chew and swallow food and drink, or (b) take nutrition by using a therapeutic source.

**Therapeutic source:** parenteral or enteral tube feeding, using a rate-limiting device such as a delivery system or feed pump.



Simple meal: a cooked one-course meal for one using fresh ingredients.



The MEA has produced two cookbooks for people with ME/CFS:

**Cooking for Me** (Book 1) has recipes that are colour-coded for ease of preparation, include meat-based and fish options, vegetarian, vegan, and gluten-free alternatives, and plenty of shortcut tips to help cut down on kitchen time.

<https://meassociation.org.uk/c8xl>

**Four Seasons** (Book 2) has six super sections packed with recipe ideas for Spring, Summer, Autumn, Winter, the Festive Season and Desserts. Plus pages for your own notes and recipe contributions from members of the charity.

<https://meassociation.org.uk/p19i>



## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

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**Therapy:** therapy to be undertaken at home, which is prescribed or recommended by, (a) a registered (i) doctor, or (ii) nurse, or (iii) pharmacist, or (b) health professional regulated by the Health Professions Council.

**Toilet needs:** (a) getting on and off an unadapted toilet, (b) evacuating the bladder and bowel, and (c) cleaning yourself afterwards.

**Unaided:** i.e., without (a) the use of an aid or appliance, or (b) supervision, prompting or assistance.



Therapy undertaken at home should be prescribed by a registered doctor, nurse, pharmacist or health professional regulated by the Health Professions Council.

## PERSONAL INDEPENDENCE PAYMENT A GUIDE TO APPLICATIONS FOR PEOPLE WITH ME/CFS

### The ME Association welcomes feedback about this guide.

Please send any comments to:

The ME Association  
7 Apollo Office Court  
Radclive Road, Gawcott  
Bucks MK18 4DF

or email: [Feedback@meassociation.org.uk](mailto:Feedback@meassociation.org.uk)

Registered charity number: 801279

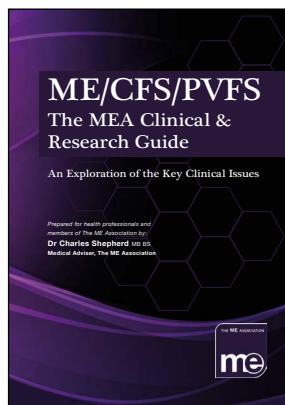
## THE ME ASSOCIATION'S 'PURPLE BOOK'

The latest edition of **ME/CFS/PVFS - An Exploration of the Key Clinical Issues** is an authoritative publication representing the most comprehensive, evidence-based summary of PVFS/ME/CFS currently available. It contains everything that health professionals and patients need to know about this devastating neurological disease and comes highly recommended.

**Price £10.00 (UK/BFPO)**

Order from the ME Association website shop:  
<https://meassociation.org.uk/carg>

Alternatively, call our office on 01280 818963  
or order online at Amazon: <https://tinyurl.com/bdfw8f5w>



## BECOME A MEMBER OF THE MEA

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family members, and anyone with a professional interest in the condition.

Annual membership costs:

£18.00 (UK residents and BFPO)

£24.00 (Mainland Europe including Republic of Ireland)

£30.00 (Rest of the World)

Visit the website shop to find out more:

<https://meassociation.org.uk/8cjm>



THE ME ASSOCIATION



**Freephone**

**0800 538 5200**

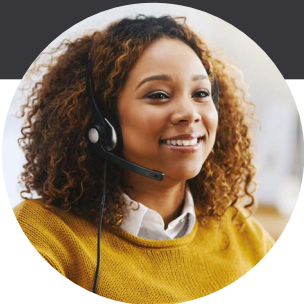
**Monday to Friday 10am - 6pm  
(Late night until 9pm on Thursdays)**

**Saturday & Sunday  
10am - 12 noon & 7pm - 9pm**

## **ME CONNECT**

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

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



### **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](mailto:meconnect@meassociation.org.uk)**



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