



The ME Association Guide to filling in your PIP forms

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The ME Association welcomes feedback about this guide. Please send any comments to **ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks MK18 4DF** or email: admin@meassociation.org.uk
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INTRODUCTION

If you think you qualify for Personal Independence Payment (PIP), then do claim it.

Don't be put off by the complexity of the form or that you will probably have to undergo a medical assessment afterwards.

You will have to accept this will be a difficult time, so work through the form slowly – doing a little bit more each day and taking care of yourself as best you can. Ask for help if anything is not clear.

You may worry – especially with the ME – that you won't be believed. You may be distressed by the need to focus relentlessly on things you can't do. But applying for benefits compels you to do this and to focus on what is wrong with you, on what you cannot do, on how you differ from 'normal' people and from the way you were when you were well.

You just have to make the full extent of your difficulties obvious to the DWP assessors. If you want the benefit, there is no other choice. So adjust your frame of mind accordingly.

Remember that nothing you have done has prolonged this illness and increased your level of disability. You have a right to this benefit. However, if you are truly overwhelmed by the process of applying for it and do not want to continue, you also have the right to pull out at any time.

SO WHAT IS PIP?

This is a benefit that is replacing Disability Living Allowance for people aged 16 to 64. There's no means test involved and you don't pay tax on it.

You cannot put in a new claim for PIP after reaching the age of 65 but, if you already receive it when you reach that age, you will be able to stay on it.

PIP is for people who need help to take part in everyday life or who have trouble getting about. It is paid to you, not to a carer, and it is based on the help you need **REGARDLESS OF WHETHER OR NOT YOU ARE ACTUALLY GETTING THAT HELP.**

To qualify, you need to have been present in Great Britain for two out of the last three years – with your normal residence in the United Kingdom, the Channel Islands, the Republic of Ireland or the Isle of Man.

You also need, at the time you apply, to have satisfied the disability test for PIP for at least the past three months and to be able to satisfy the DWP that the disability will continue for at least a further nine months.

If you are applying to be transferred out of DLA, the three-month initial qualifying period does not apply. Neither does it apply if you are covered by the linking rule:

The linking rule applies if you are under 65 and need to reclaim PIP within two years of a previous award ending – provided the later claim is for the same PIP component you received before, based on the same health condition as before or on a condition that developed out of the previous condition, and that you still meet all the other qualifying criteria.

If you are 65 or over, the same linking rules apply, but the claim must be made within one year, rather than two, of the end of the previous award.

For those in hospital or in a care home

If you are in a care home where part or all of the costs are met from public funds, the daily living component of PIP ends after 28 days, but the mobility component continues to be paid.

If you are a hospital in-patient, neither component is payable after 28 days. But, if you already have a Motability vehicle, there is a three-year period of grace from April 2013 before the new rules on hospital stays and the mobility component apply.

Payment of PIP resumes immediately on leaving the care home or hospital, providing you still qualify for it.

Terminal illness

An enhanced rate of the daily living component will be paid automatically, if your death can reasonably be expected within six months. The mobility component will also be made without going through the three-month qualifying period, providing you qualify for it.

PIP and DLA – spot the differences

Like DLA, PIP has two components – the daily living component for help taking part in everyday life and the mobility component for help with getting around.

And each is paid at two different levels – a standard rate and an enhanced rate, depending on how severe your limitations are assessed to be. But there is no equivalent to the DLA lowest care rate.

Unlike DLA, PIP does not separate your needs into day and night needs. Your ability to carry out each activity is considered over a 24-hour period.

Unlike DLA (but like Employment and Support Allowance), your eligibility for PIP is assessed using a points system. It is very important to keep the points system in mind when completing the application form (see the Appendix, pages 25-29).

You are far more likely to be given a fixed-term award, as opposed to an indefinite award, on PIP than you were on DLA. The length will vary between two and 10 years, depending – in the opinion of the DWP – on how likely your condition will change.

The activities test

The form asks questions about 12 different activities :

1. Preparing food
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Washing and bathing
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating verbally
8. Reading and understanding signs, symbols and words
9. Engaging with other people face-to-face
10. Making budgeting decisions
11. Planning and following journeys (*used in the test for the mobility component*)
12. Moving around (*also used in the test for the mobility component*).

Each of these activities is divided into a number of descriptors that carry scores ranging from 0 to 12. The descriptors describe tasks of varying degrees of difficulty.

You qualify for the standard rate of the daily living component by scoring 8 points, and for the enhanced rate by scoring 12 points. The same with mobility component – 8 points for the standard rate, 12 points for the enhanced rate.

To make their assessment, the DWP will look at your claim form, any further evidence you submit, and the report from the face-to-face medical assessment. Most claimants will be required to have a face-to-face assessment.

Variable and fluctuating conditions

For someone with a variable and fluctuating condition, such as ME/CFS, it is important to remember that you can score points for an activity even though you can only carry it out occasionally, or imperfectly, or very slowly; or if you only have symptoms for part of a day, or for part of a longer period.

If you are already claiming DLA – the transfer to PIP

The DWP will send you a letter to explain that DLA is ending for people of working age and that you must make a claim for PIP or your benefit will stop. Do remember that you will not be transferred to PIP automatically. You have to put in a claim for it.

You will then have 28 days from the date of the letter to make your initial claim by telephone, or complete the paper claim form PIP1 and return it to the DWP. The 28 days can be extended in exceptional circumstances, for example, if you have had to go into hospital.

If you have not made a claim within 28 days and not been granted an extension, your DLA will be suspended for four weeks. If you make a claim within these four weeks, your DLA will be restored. But you will lose your DLA if you have still not made a claim for PIP within eight weeks.

If you then make a claim within the eight week period, your DLA will continue to be paid until a decision has been reached on whether you are entitled to PIP. The decision, favourable or not, will not take effect for four weeks after your next DLA pay day.

However, if you have been asked for further information, or to attend a medical, in the course of your claim and have not done so, your DLA award will end 14 days after the decision that you failed to comply.

If, as a result of being on DLA, you receive other benefits or concessions, you will continue to get these benefits while you are being assessed for PIP.

TO START YOUR CLAIM FOR PIP – THE PIP1 FORM

Phone the DWP on 0800 917 2222 (Textphone: 0800 917 7777). From an ordinary landline, these are free phone calls but costs will vary if you use a mobile or other device. So if you are concerned about the cost of the call, ask the DWP to call you back.

If your English is not fluent, ask the agent taking your call to use the DWP translation service: **'thebigword'**.

If you need support, a helper can make the call for you but you need to be present to confirm that they can speak on your behalf.

If you need support on the phone but don't have anyone to help you, you still have to make the initial call but can then ask for a paper claim form to be sent to you or request a home visit from a DWP visiting officer to help you complete the form.

You can also request a PIP1 form by writing to:

**Personal Independence Payment New Claims
Post Handling Site B
Wolverhampton
WV99 1AH**

The initial claim process collects basic information about you and asks whether you have one of the following conditions:

- * Mental health condition
- * Behavioural condition
- * Learning difficulty
- * Developmental disorder
- * Memory problems

This is to find out whether you need extra support during the claim process. But, at this stage, you will not have to answer detailed questions about your disability or health.

You will also be asked a number of other questions and will need the following information to hand in the course of the call:

- * Your National Insurance number
- * Your address
- * Your date of birth
- * Your bank or building society details
- * Your telephone number
- * The name of your doctor or health worker you want the DWP to contact
- * Details of any time you've spent out of the country
- * Details if you are in a care home or hospital, or if you have recently been in a care home or a hospital.

At the end of the call, the agent will read out a declaration and ask you to agree to it. If you are a new claimant (not someone moving from DLA to PIP), the date of the declaration will be the date your PIP will start if your claim is successful. So keep a record of the date you call.

Once you have completed the telephone interview, you will be sent a copy of your completed PIP1 form to check, sign and return. If it is not returned within the time limit given in the accompanying letter, your claim will be closed. So, if you can, get a certificate of posting when you return the form.

If you have one of the health conditions listed above, you should be given extra time to complete and return the form.

NB You cannot, at present, fill in any of the application forms for PIP online.

CONFUSED?

The private Benefits and Work website has an online PIP checker so you can score yourself for the daily living and mobility components of PIP just by clicking with your mouse. Try it out at: <https://tinyurl.com/ybnulsjr>

THE NEXT STAGE OF THE CLAIMS PROCESS

The DWP will send you the PIP2 form ('How your disability affects you'), once they've received a signed PIP1.

The form is complicated. If you can, get hold of some rough paper and map out your answers to all the questions in advance. It could save an awful lot of aggravation later on.

Returning the PIP2 form

When it arrives in the post, you will have a month to complete it. If it is late arriving, so the deadline is less than a month away, contact the DWP and arrange a new deadline. If you have a strong reason for returning the form late, inform the DWP as soon as possible.

Before returning the form, always photocopy it as well as any pages you may have added, and any written evidence you are submitting. It's best to submit copies of medical evidence, keeping the originals for your records. Write your name and National Insurance number at the top on any additional pages.

The DWP will refuse your claim if you cannot show good cause for any delay. If you are claiming DLA, your DLA will stop.

However, if you do not return the PIP2 form and you have been identified from your PIP1 as having a mental or cognitive impairment, Atos and Capita – the assessment companies involved – have been told that they must still make an assessment. This should be done either by collecting additional evidence – which might include phoning you –and/or by asking you to attend a medical. The evidence will then be passed to the decision-maker in the normal way.

What you need to know before completing the form (VERY IMPORTANT)

When completing the PIP2 form, you need to give details of any problems you have with each activity as a result of any physical and/or mental health conditions and learning difficulties. You should also include any problems caused by the effects of any medication.

Your entitlement will be assessed against a set of descriptors that describe different levels of ability to carry out each activity.

For people with ME/CFS, it is particularly important to remember that 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 the task in question **'reliably'**.

'Reliably' means:

- * 'Safely' – in a way unlikely to cause harm to yourself or others
- * To an acceptable standard
- * 'Repeatedly' – as often as is reasonably required
- * 'In a reasonable time' – no more than twice the maximum amount of time a 'normal' person would take.

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.

Fluctuating conditions

If your condition varies from day to day, a descriptor will apply to you if it reflects your ability for the majority of days, i.e. more than 50% of days. This 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 over such a long time, take a recent shorter period and work it out from there. It's a good idea to keep a diary for a while to provide a picture of your condition over time.

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.

So if you need an aid to wash yourself on 90% of days (2 points) but on 55% of days you need help to get into your bath or shower (3 points), you will score 3 points for the washing and bathing activity.

If you do not satisfy any descriptor for over 50% of the time but if two or more descriptors, added together, apply to you for more than 50% of the time in respect of one activity, you will get points for the descriptor that applies for the greatest number of days or, if they both apply for the same number of days, the one that scores the most points.

So if you need an aid to help you wash on 30% of days (2 points) and help to get in and out of the bath or shower on 35% of days (3 points), you will score 2 points for the washing and bathing activity because needing an aid is the descriptor that applies most often, and no descriptor applies for 50% of days. But should you need both an aid and help on 30% of days, you will score 3 points: the higher-scoring descriptor is the one that applies.

If your condition varies over the day, you are regarded as satisfying a descriptor if your condition changes at any point in the day. So if you function well for a short time each day, you can still score points if you do not satisfy the descriptors for the entire day.

Aids and appliances

1. GAINING POINTS FOR AIDS AND APPLIANCES

Aids and appliances are very important in relation to PIP and you should mention any that you use on your claim form. 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.

So these include not only specialised disability aids, but also everyday ones such as electric tin openers or food processors. Items that might more commonly be thought of as adaptations, such as a hand rail, are also included. Again, if your home has been adapted in any way to accommodate your disability, mention this on the PIP2 form.

You will need to show that you use aids and appliances not only for their convenience, but because your impairment makes their use necessary.

If it is accepted that you need aids in relation to 4 daily activities on the claim form, it would be possible for you to qualify for the daily living component on this basis alone – since the use of an aid scores you 2 points and you require 8 points for the standard rate of daily living component.

2. LOSING POINTS FOR AIDS AND APPLIANCES

The downside is that your score is calculated on the basis that you are using all aids and appliances that you can be 'reasonably expected' to use. So where you say that you cannot carry out an activity, or you need help from another person to carry it out (which may score you more points), a decision-maker may decide that you could carry out the activity unaided if you used a suitable aid or appliance that you could reasonably be expected to use.

When deciding whether it is reasonable to expect you to use an aid or appliance that you don't currently use, but which would mean you could carry out an activity, Capita and Atos have been told by the DWP to take into account whether you possess the aid or appliance; whether it is widely available, and at what cost; whether it is medically reasonable for you to use it; whether a health professional would advise its use; whether it is easy to store; and whether you have another health condition that would make it impossible for you to use.

Some useful definitions

Assistance

DWP guidance to Capita and Atos is that:

“Assistance is support that requires the presence and physical intervention of another person to help the claimant complete the activity – including doing some but not all of the activity in question. To apply, this only needs to be required for part of the activity.”

Prompting

The guidance is that:

“Prompting is support provided by another person by reminding or encouraging a claimant to undertake or complete a task or explaining it to them but not physically helping them. To apply, this only needs to be required for part of the activity.”

Supervision

Here, the guidance is that:

“Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the claimant. The risk must be likely to occur in the absence of such supervision. To apply, supervision must be required for the full duration of the activity.”

COMPLETING THE PIP2 FORM CALLED 'HOW YOUR DISABILITY AFFECTS YOU'

Tick boxes

Think carefully before ticking the boxes.

Each question has a series of tick boxes as well as a blank box in which you can add further details and clarify your answers. Use the blank boxes to give a full account of the difficulties you have with the activity you are being asked about. Even if you can do an activity, if you are not able to do the activity reliably, then it will probably mean that it would be better for you to tick the 'no' box and for you to describe your difficulties fully in the blank box.

THE STRUCTURE OF THE FORM

QUESTIONS 1 and 2 ask about your health professionals, health conditions, treatments and medication. List not only the medical professionals you see (including OTs and physiotherapists, etc) but social workers, support and care workers or counsellors. But bear in mind that, just because you have listed them, does not mean that Atos or Capita will contact them.

Try to get written evidence from them yourself. Do not delay sending off your claim form because you are waiting for this evidence.

If you do not see your GP much because they are unable to offer any help, you could explain this here. You may also have difficulties getting to the surgery, so perhaps include this as well. If you have phone or Skype consultations or home visits, explain this too.

If you have seen a consultant but been discharged as they are unable to help further, add this. Write on the form if there is no specialist ME service in your area.

Make sure you list all your health conditions, physical and mental. You might just want to bullet point all your ME symptoms,

In the section on medication (**QUESTION 2b**), list all the medication you have and treatments you may have had. The assessors may well 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, explain this. Otherwise it may be assumed that if, say, you rely on over-the-counter painkillers, you are not in serious pain. In fact, you may prefer to put up with the pain rather than deal with the side-effects of prescription drugs and you should say so.

If you have had treatment in the past that shows how serious your condition is, then list it here – even if it was years ago. For instance, you may have attended a pain clinic, been prescribed physiotherapy or been fed by tube.

DAILY LIVING ACTIVITIES

QUESTION 3. Preparing food

This question is all about your ability to prepare a cooked, one-course meal for one person using fresh ingredients. You are scored on how well and safely you can use a normal cooker, a microwave or do things like peeling and chopping vegetables and opening tins.

Check the Appendix (pages 25-29) to find out what the regulations say you score points for.

Some further, useful definitions:

Prompting

'Prompting is support provided by another person by reminding or encouraging a claimant to undertake or complete a task or explaining it to them but not physically helping them. To apply, this only needs to be required for part of the activity.'

Supervision

'Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the claimant. The risk must be likely to occur in the absence of such supervision. To apply, supervision must be required for the full duration of the activity.'

Assistance

'Assistance is support that requires the presence and physical intervention of another person to help the claimant complete the activity - including doing some but not all of the activity in question. To apply, this only needs to be required for part of the activity.'

But remember the following points:

The regulations say that:

'Prepare' means making food ready for cooking or eating. This includes washing, peeling and chopping but we would also include things like opening tins and packets and weighing and measuring ingredients.

'Cook' means heating food at or above waist height.

'Simple meal' means a cooked, one-course meal for one using fresh vegetables. Although the regulations say 'fresh' ingredients, this appears to be intended to exclude ready meals rather than meaning that you can't add tinned or dried foods to fresh meat and vegetables.

Remember 'reliably'

Remember that you should not be considered able to do something if, for

example, you aren't safe doing it or it causes you pain or discomfort or it exhausts you or you're very slow at doing it.

If it's not safe for you to handle sharp knives or hot pans, for example, then say so. If preparing a meal would exhaust you or it would take an extremely long time even with assistance or supervision, then explain this.

When completing **QUESTION 3a**, DWP guidance suggests that in addition to the use of aids or appliances while cooking, adaptations in the kitchen also count. The kind of aids, appliances and adaptations that might be relevant include an electric can opener, a ring-pull can opener, a jar opener, a slotted spoon, a perching stool, prostheses, a knob and tap turner, single-lever arm taps, a cooking basket, timers, a plate-holder, an auto-chopper, lightweight pans, easy/comfort grip utensils, a peeler and clammer and a kettle-tipper.

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.'

Caution! Decision-makers may argue that you could use an aid or appliance as an alternative to having supervision or assistance from another person. If there is a reason why the aid or appliance would not mean you didn't need help, explain why. For example, if timers wouldn't help because you would forget to set them or get confused about why they were going off, or if a perching stool wouldn't help because you have dizzy spells and might fall off, then explain this.

In **QUESTION 3b**, 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 help you need, then tick the 'Yes' box and give details in the 'Extra information' box on the next page.

QUESTION 4. Eating and Drinking

This activity considers your ability to eat and drink.

You may wish to think about whether you need help with motivation to eat if you are feeling too exhausted and ill to eat. Some people with severe ME need tube-feeding and, if this applies to you, it will be necessary to describe the process involved and any help you need with feeding yourself.

If you use any aids or adaptation to help you eat and drink, mention them in this section even if you have described them in more detail in answers to **QUESTION 3.**

QUESTION 5. Managing treatments

This activity considers your ability to monitor any health conditions, to manage your medication and to cope with treatments.

You may wish to think about whether you are able to take your medication without help, whether you have the ability to monitor and detect changes in your health condition and to manage treatments, like physiotherapy and pacing.

Perhaps you need help with any form of activity management that you are meant to do. If your GP, OT, physiotherapist or local ME clinic has asked you to carry out any activity management or to keep a diary of your daily activities, you could mention any help you need with this here.

You may find it very difficult to pace without help due to exhaustion and mental fatigue, so you may need assistance with managing this. Describe why you need the help and what happens to you if you do not get the help that you need.

QUESTION 6. Washing and bathing

This activity is about your ability to wash and bathe and to use a bath or shower. If you often do not wash or bathe due to exhaustion or feeling too ill, say so here.

If you have any problems with washing yourself, perhaps because of problems with grip or pains that make it hard to hold soaps or reach certain parts of your body, explain this. Perhaps you feel faint on standing up (as a result of orthostatic intolerance) and standing up in the shower or getting in or out of the bath could be dangerous.

Perhaps you don't bathe as often as you would like because you don't get the help you need, or perhaps it is the only thing that you have the energy to do in a day.

QUESTION 7. Managing toilet needs

This activity considers the ability to get on or off the toilet and to clean yourself afterwards.

If you rely on a commode but it doesn't get emptied as often as you like because there is no one around to help, put that in the blank box.

QUESTION 8. Dressing and undressing

This activity looks at your ability to dress and undress yourself.

If you often do not get dressed or undressed because of exhaustion or feeling too ill, you can explain this here. If you have any problems with dressing yourself, perhaps through dizziness, fainting or problems with grip, muscle weakness or pains that make reaching or bending difficult, explain this here.

Perhaps you don't get the help you need to do this as often as you would like or perhaps it is the only thing that you have energy to do in a day. Or it might be that you are unable to wear the clothes you like, as nowadays you have to rely on items that can be pulled on easily and fastened with Velcro rather than buttons and zips.

Perhaps you often stay in your nightclothes in order to conserve energy. If you can do this activity but it takes a long time and aggravates your symptoms, mention this here. You may need to keep resting while dressing or undressing.

QUESTION 9. Communicating

This activity is about your ability to communicate – both understanding others and being understood yourself.

The descriptor mentions 'communication support'. This means support from a person who is trained or experienced in communicating with people with specific communication needs.

It could be worth including information here about the effect communication has on you. Does talking and listening have an effect on your health? Do you feel exhausted after conversations or as a result of having to listen and take in information. It is also worth pointing out that cognitive dysfunction - problems with concentration and attention span, short-term memory, information processing - is an important and sometimes very disabling symptom of ME/CFS.

Perhaps you have to time when you can have conversations and plan them into your day – for example, you may only be able to communicate effectively in the morning and need to rest afterwards. And there might be times when you are simply too unwell to communicate with other people. Do you put off making phone calls due to your illness?

QUESTION 10. Reading

This section is about your ability to read and understand written signs, symbols and words in your own language.

Most relevant for people with ME might be the ability to understand written information. As a result of your illness, you may now have problems with processing information – something you never experienced before you were ill.

It may be worth stating your problems with understanding information here. Do you now need to call for help with forms and paperwork?

QUESTION 11. Mixing with other people.

This activity is about your ability to get on socially with other people when you see them face-to-face.

You may want to describe any problems with extreme fatigue or poor concentration that mean you have difficulty following what people are saying to you and responding appropriately.

If you become anxious in social situations, you could describe this here. Perhaps you are not able to engage socially reliably and repeatedly, even if you can do so for some of the time. As a result of your illness, you may have lost confidence in dealing with these situations and may even avoid them due to the effect that they have on you.

QUESTION 12. Making decisions about money

This deals with your ability to handle your money.

Do you now need help sorting out your budgeting and money as a result of your illness? Perhaps you become overwhelmed and find it hard to make decisions about budgeting? Maybe you are too exhausted to deal with paperwork and bills and need help with managing these.

MOBILITY ACTIVITIES

QUESTION 13. Going out

This section is about your ability to work out, plan and follow a journey.

This question may be hard for people with ME to score points on unless they also have problems with anxiety or panic attacks. Many people with ME describe cognitive difficulties with planning and feel disoriented and confused when out so this kind of information may be worth including here.

Check the descriptors carefully (and the definitions) to see whether you think you might meet them.

When completing this question, think about any problems that you have with going out. Do you experience anxiety or panic attacks? Can you describe how you feel or what happens when you feel anxious or have a panic attack? It is likely that you will have both emotional and physical symptoms.

Do you feel overwhelmed in noisy places and are you noise or light sensitive? Perhaps you avoid places that are too crowded or noisy.

Does your condition mean that you get confused and disorientated when you are out? Do you sometimes feel so ill when out that you need someone to take you home?

Remember to include the effects of any medication you take. Does it make you drowsy, apathetic or lethargic so that it is difficult to motivate yourself to undertake a journey? Does it make you too anxious or confused to undertake a journey? Does it help to have someone with you to ensure your safety and help you manage any feelings of anxiety?

If you can think of examples of what has happened when you have gone out or examples of things that you are unable to do unless you have someone with you, put them down here.

QUESTION 14. Moving around

This activity is all about your ability to physically move about. The DWP say that this activity should be judged in relation to the type of surface normally expected out of doors, including obstacles such as pavements and kerbs.

When considering which box to tick at **QUESTION 14a**, make sure that you look at the descriptors for this activity. Remember to always take into account the key issues involving 'safely, reliably and repeatedly' and whether you can walk the distance 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, you may want to tick the box stating that you

can walk less than 20 metres or the between 20 and 50 metres box.

You can then explain in more detail about the problems that you have with walking, in the information section. Tell them how far you can walk before you experience pain, severe discomfort, fatigue, breathlessness, muscle weakness, etc. You also need to explain if you are not able to walk repeatedly and reliably.

If there are days that you are housebound or bedbound, you need to explain that you are not able to walk any distance out of doors on those days.

You may be able to walk a short distance but this exertion may then cause an increase in your symptoms and may result in you needing complete bed rest for several hours or even days.

It is worth considering whether there are any aids that would help you to walk as the DWP may argue that you could use certain aids. If you use a wheelchair to cover the distance in **QUESTION 14a** and can only cover this distance by wheelchair, then you should score the points for the activity.

Other aids will probably be of limited use to people with ME. A stick may help with balance problems but would not help reduce levels of exhaustion and fatigue. It may be that it is not possible to use a stick due to pains in the hands or arms or because of muscle weakness or a lack of grip in the hands. If an aid would be useful, it does not rule out you scoring here so have a careful look at the descriptors and think about exactly what you want to say.

It came as an enormous shock when, in December 2012, the DWP produced their final version of the PIP points system and revealed that the maximum distance you need to be able to walk to qualify for higher rate mobility had been slashed from 50 metres to 20 metres. There had been no reference to this in previous drafts of the descriptors.

Bear in mind that, if you score points for 'Planning and following journeys', you can add these to any points you score for 'Moving around'. But the reduction in distance will make it more difficult for you to get the enhanced rate mobility PIP award.

QUESTION 15. Additional information

Add any information not included elsewhere, summarise any important points that you wish to make, recap important points and give some background information about your condition and how it restricts you. Perhaps you could briefly say how your life has changed and what you have had to give up since becoming ill.

The 'What happens next?' section of the form

If you would have difficulties travelling to attend a face-to-face medical, give the details here. If travelling and then participation in the interview would make your symptoms worse, say so. You may already be housebound and unable to get there. You can ask for a home visit and will probably need to provide medical evidence confirming that this is required.

If you require certain facilities at the assessment centre, state what they are. It might be somewhere where you could lie down to rest or a room with the lights turned off. Think about the things that would help you manage on the day.

We would suggest that you have someone with you and that you say you will be bringing someone with you on the day.

WHAT HAPPENS NEXT?

As with PIP1, this form cannot yet be completed online.

When you have completed the form and signed the declaration, remember to make a photocopy of every page in the form, any additional pages you include and also make a copy of any supporting evidence you want to submit (keeping the original copies of any medical and other supporting evidence. You would be surprised at how many times we hear of these forms being lost in the post or mislaid after they have reached their destination).

Each additional sheet should have your name and National Insurance number written clearly at the top.

You are then ready to catch the post!

ONCE THE FORM IS RETURNED, WILL I HAVE A MEDICAL?

The Atos or Capita health professional will first review the form and any additional evidence you have submitted and decide whether to send for further evidence.

They will then either make an assessment based on the information they already have or call you in for a medical. Usually, though, they will carry out a medical.

Unlike for Employment and Support Allowance, where you cannot be found fit-for-work without a face-to-face assessment, the health professional can decide not to carry out a medical even if they are going to assess you as scoring zero points.

Guidance from the DWP states paper-based assessments are appropriate where:

- * The evidence indicates that it is unlikely that the claimant's condition has any impact on any of the daily living and mobility activities (i.e., the decision-maker thinks you obviously don't qualify for PIP)
- * The evidence indicates that the claimant's condition has a significant impact on many of the daily living and mobility activities (i.e., the decision-maker thinks you obviously do qualify)
- * There is strong evidence on which to decide the case and where a face-to-face consultation is likely to be stressful to the claimant

The medical

Medicals will be conducted by Capita in Wales and Central England, and by Atos in all other parts of England and Scotland. Most Atos health professionals are physiotherapists, while Capita employ mostly nurses.

You will be given at least seven days' notice in writing of a medical unless you have agreed otherwise.

Capita say they will see most claimants at home, but Atos will require most to attend an examination centre. If you are unable to attend a centre, you should be offered a medical at home. You will need to provide evidence from a doctor explaining that you are too ill to travel.

What happens at the medical?

The health professional you see is supposed to have read everything on your file before starting the assessment – including your questionnaire and supporting evidence, and any information from previous PIP assessments.

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 your home, your work activity and social activities.

You should then be asked about a typical day, including details of how your conditions affect your ability to perform everyday tasks. You should be asked about 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.)

Health professionals are warned that a 'snapshot' of your condition on a particular day is not adequate and that they need to consider your condition over time.

The assessor may then carry out a brief physical examination, checking things like your eyesight, your blood pressure and the range of movements in your limbs, if any of these are relevant to your condition.

They will be observing things like your hearing ability, your walking ability, your ability to concentrate, to stand, sit, move around and use your hands and your ability to retrieve things such as a handbag on the floor beside you.

Try to answer questions as fully as possible, remembering to include the 'buts...' in your replies.

For instance say:

'Yes I can get out of bed, but not until about 15 minutes after I wake up because I am so stiff first thing in a morning.'

'Yes, I can cook a simple meal, but on most days I am too exhausted and confused by the afternoon to prepare anything but a bowl of cereal or a sandwich.'

Finally, after you have gone, they will list which descriptors they consider apply to you and justify their conclusions.

Recording medicals

The DWP say that the recording of medicals is not part of the assessment process.

They also say that claimants are welcome to bring their own recording equipment, with the huge provisos that it must be a dual tape or CD recorder, that you must inform Atos or Capita in advance and that you must give a copy to the health professional at the end of the assessment.

Home visits

While these are a possibility, it seems that Capita are far more likely to carry out a home visit than Atos. If you need a home visit, make this clear and explain the reasons why. Your request is likely to have more chance of success if you can include a letter from your GP or consultant confirming that you require a home visit.

What happens now?

The case manager at the DWP will now look at all the evidence to decide if you meet the criteria for an award of PIP. Once they have reached a decision, you will receive a decision letter telling you the result.

If your claim has not been successful or is at a lower rate than it was, it is likely that you will also get a phone call.

If you are not happy with your award

If you are not happy with the decision you have the right to request a reconsideration, If you are still not happy after this, you need to appeal straight to the Tribunals service. There are time limits with both procedures.

This is a new way of doing things as a result of the change to the law, so if you have appealed in the past this will be a different procedure.

You need to ask for a reconsideration within a month of them sending the decision letter.

Other sources of support

CITIZENS ADVICE

Advice on many topics – including benefits applications and appeals, through your local Citizens Advice Bureau (in all local phone directories) or at www.citizensadvice.co.uk

DIAL (NOW SCOPE)

Network of local disability information and advice services run by and for disabled people. Check your telephone directory or visit www.scope.org.uk/dial and click on 'Find your local DIAL'. Or phone 01302 310123 to get details of support in your area.

DISABILITY RIGHTS UK

Useful fact sheets on their website and publishers of the very detailed Disability Rights Handbook, which is Britain's most comprehensive guide to benefits and services for disabled people. Visit www.disabilityrightsuk.org

ME CONNECT

Information and support line of the ME Association. Open daily 10am-12noon, 2-4pm, 7-9pm on 0844 576 5326. Email admin@meassociation.org.uk if you find it too difficult to talk. We have a team of excellent, trained volunteer listeners who can help with all sorts of information relating to ME/CFS. But they are not qualified to give detailed benefits, medical or other professional advice.

APPENDIX: ACTIVITIES, DESCRIPTORS AND THE SCORING SYSTEM

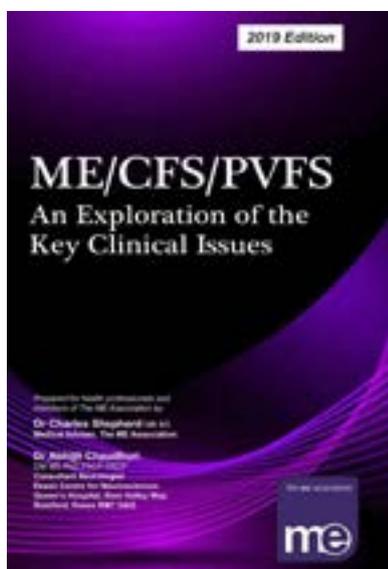
DAILY LIVING COMPONENT ACTIVITIES	
Activity	Descriptors
1. Preparing food	a. Can prepare and cook a simple meal unaided - 0 points
	b. Needs to use an aid or appliance to either prepare or cook a simple meal – 2 points
	c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave – 2 points
	d. Needs prompting to be able to either prepare or cook a simple meal – 2 points
	e. Needs supervision or assistance to either prepare or cook a simple meal – 4 points
	f. Cannot prepare and cook food – 8 points.
Activity	Descriptors
2. Taking nutrition	a. Can eat and drink unaided – 0 points
	b. Claimant 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 (i.e., tube feeding using a rate-limiting device such as a delivery system or feed pump) 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.
Activity	Descriptors
3. Managing therapy or monitoring a health condition	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

	<p>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 (iii) supervision, prompting or assistance to monitor a health condition – 1 point.</p>
	<p>c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week – 2 points.</p>
	<p>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</p>
	<p>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</p>
	<p>f. Needs supervision, prompting and assistance to be able to manage therapy that takes more than 14 hours a week – 8 points.</p>
Activity	Descriptors
4 Washing and bathing	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
Activity	Descriptors
5.Managing toilet needs or incontinence	a. Can manage toilet needs or incontinence unaided – 0 points
	b. Needs to use an aid or appliance 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
Activity	Descriptors
6. Dressing and undressing	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
Activity	Descriptors
7. Communicating verbally	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
	d. Needs communication support to be able to express or understand complex basic information – 8 points
	e. Cannot express or understand verbal information at all even with communication support – 12 points
Activity	Descriptors
8. Reading and understanding signs, symbols and words	a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses – 0 points

	<p>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</p> <p>c. Needs prompting to be able to read or understand complex written information – 2 points</p> <p>d. Needs prompting to be able to read or understand basic written information – 4 points</p> <p>e. Cannot read or understand signs, symbols or words at all – 8 points</p>
Activity	Descriptors
9. Engaging with other people face to face	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 that would result in a substantial risk of harm to the claimant or another person – 8 points
Activity	Descriptors
10. Making budgeting decisions	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
MOBILITY COMPONENT ACTIVITIES	
Activity	Descriptors
11. Planning and following journeys	a. Can plan and follow the route of a journey unaided – 0 points
	b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant – 4 pts

	c. For reasons other than psychological distress, cannot plan the route of a journey – 8 points
	d. For reasons other than psychological distress, cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid – 10 points
	e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant – 10 points
	f. For reasons other than psychological distress cannot follow the route of a familiar journey without another person, an assistance dog, or an orientation aid – 12 points
Activity	Descriptors
12. Moving around	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
	f. Cannot, either aided or unaided: (i) stand OR (ii) move more than 1 metre - 12 points



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