TIPS TO COMPLETE THE PIP FORM - M.E

FACTSHEET

What you need to know before completing the form
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.
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 means:** must be considered for each activity and will be considered as an integral part of the information-gathering process whether at a face-to-face assessment or during a paper-based review.

***Safely:** This means you must be able to undertake them in a way that is unlikely to cause harm to you or anyone else. This could be either during or after you have done the activity. For the purpose of PIP, something is unsafe only if harm is likely to occur; it is not sufficient for you to feel harm may occur.

***To an acceptable standard:**This means that the task must be done to a standard that would reasonably be acceptable to most people.

***Repeatedly:** This means as often as reasonably required. For example if you are able to prepare a meal once without help, but the exhaustion from doing this means that you could not prepare another meal that day,
you would be treated as being unable to prepare a meal unaided. This is because it is reasonable to expect someone to be able to prepare more than one meal a day.

***In a reasonable time:**This means not more than twice as long as the maximum amount of time that a person without your health condition or impairment would normally take to complete that activity.
Pain, fatigue, breathlessness, nausea and motivation etc are all 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 the time, i.e 51% which will be considered over 12 months and looking back three months and forward nine months.
It's helpful to keep a diary for a week or so to provide a picture of your condition over time.

Aids and Appliances

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 ie extra bannister /hand rail (ii) includes a prosthesis.
These include not only specialised disability aids, but also everyday aids such as electric tin openers or Grabber stcks. If your home has been adapted in any way to accommodate your disability, mention this in the form.You will need to show that you use aids and appliances because your impairment makes using them necessary.
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.

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.

To 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 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.

QUESTION 3a

In addition to using aids or appliances while cooking, adaptations in the kitchen also count. The kind of aids, appliances and adaptations that might be relevant include:

- electric can/jar opener.
- ring-pull
- slotted spoon
- perching stool
- prostheses
- knob and tap turner
- single-lever arm taps
- timers
- plate-holder
- an auto-chopper
- lightweight pans
- easy/ comfort grip utensils
- peeler and clamper
- kettle-tipper

DWP guidance 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.

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 give details

QUESTION 4. Eating and Drinking

This activity considers your ability to eat and drink.

You need to consider whether you need help with motivation to eat if you are feeling too exhausted. Some people with severe ME need tubefeeding 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 previously

QUESTION 5. Managing Treatments

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

Consider whether you are able to take your medication without help, whether you have the ability to monitor and detect changes in your condition and to manage treatments, like physiotherapy and pacing.

Do you need help with activity management. If your GP, OT, phsyiotherapist or local ME clinic have asked you to carry out any activity management or to keep a diary of your daily activities, mention here any help you need.

If you find it very difficult to pace without help due to exhaustion and mental fatigue, and you need assistance managing this, describe why you need help and what happens if you don't get it.

QUESTION 6. Washing and Bathing

This activity is about your ability to wash, bathe and use a shower. If you don't often wash or bathe due to exhaustion or feeling too ill, say so.

If you have problems washing yourself, perhaps because of poor grip or pain, making it difficult to hold soaps or reach certain parts of your body, explain this.

You may feel faint on standing up as a result of ie, orthostatic intolerance 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, tell them this.

QUESTION 8. Dressing and Undressing

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

If you don't get dressed or undressed often because of exhaustion or feel too ill, explain this here. If you have any problems with dressing yourself, hrough dizziness, fainting or problems with grip, muscle weakness or pains that make reaching or bending difficult, tell them.

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

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

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.

You could mention here about the effect communication has on you, ie, 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's worth pointing out that cognitive dysfunction ie, problems with concentration and attention span, short-term memory, information processing is an important and often a very disabling symptom of ME/CFS.

Do you have to time when you can have conversations and plan them into your day, ie, you are only able to communicate effectively in the morning and need to rest afterwards. There may be times when you are too unwell to communicate with others. If you put off making phone calls due to your illness, mention this here.

QUESTION 10. Reading

This 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, you may have problems with processing information. Do you now need to call for help with forms and paperwork? State your problems with understand information here.

QUESTION 11. Mixing With Other People.

This activity is about your ability to get on socially with others when seeing them face-to-face. Describe any problems you have 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, or you are unable to engage socially, reliably and repeatedly, even if you can do so for some of the time. As a result of your condition, you may have lost confidence in dealing with these situations and avoid them due to how it affects you.

QUESTION 12. Making Decisions About Money

This is about your ability to handle your money.

Do you now need helping sorting out your budgeting and money as a result of your condition?

Are you overwhelmed and find it difficult 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 looks at your ability to work out, plan and follow a journey.

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 and any problems you have with anxiety or panic attacks.

Consider any problems you have with going out. Do you experience anxiety or panic attacks, if so describe how you feel or what happens when you feel anxious, panicked 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 so you avoid places that are too crowded or noisy.
- does your condition mean you get confused and disorientated when you out?
- do you sometimes feel so ill 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 things that you are unable to do unless you have someone with you, explain 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.

Remember to take into account issues involving ‘safely, reliably and repeatedly’ and whether you can walk a distance in a reasonable period of time.

For example: if you can walk 10-20 metres but with severe discomfort then you cannot do this safely, reliably or repeatedly. Explain the problems that you have with walking ie, how far you can walk before you experience pain, severe discomfort, fatigue, breathlessness, muscle weakness, etc, this may be straight away or after a few metres.

If you have days when you are housbound/bedbound, explain that you are unable to walk any distance out of doors or indoors on those days.

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

Consider whether there are any aids that would help you walk as DWP may argue that you could use certain aids. If you use a wheelchair to cover distance and can only do this by wheelchair, then you should score the points for this activity.

Other aids will probably be of limited use to those with ME. A stick may help with balance problems but would not help reduce levels of exhaustion and fatigue. It may be impossible to use a stick due to painful hands/arms, muscle weakness or a lack of grip.

QUESTION 15. Additional Information

Add any information you haven't included in the form, summarise any important points you wish to make, recap important points and give background information about your condition and how it restricts you. Say briefly how your life has changed and what you have had to give up since becoming ill.

If you would have difficulties travelling to attend a face-to-face assessment, give details.

If travelling and then participation would +cause extreme fatigue and make your symptoms worse, say so. You may already be housebound and unable to attend.

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, ie, a room with the lights turned off, accessable toilet, no stairs etc, think about what would help you manage on the day.

We advise that you have someone with you on the day.

The Assessment:

You will be given at least seven days' notice in writing of a medical unless you have agreed otherwise. If you are unable to attend a centre, you may be offered one at home.

The assessor you see is supposed to have read everything on your file before starting the assessment, ncluding 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 will be asked about your home, your work activity and social activities.

You will then be asked about a typical day, including details of how your conditions affect your ability to carry out everyday tasks. The assessor may carry out a brief physical examination, checking things like the range of movements in your limbs, if any of these are relevant to your condition.

They will be **observing** your hearing ability, your walking, your ability to concentrate, to stand, sit, move around and use your hands and how you retrieve things such as a bag if it's on the floor beside you, we advise not to carry a bag or ask the person with you to do this for you.

Try to answer questions as fully as possible, remembering to include the 'buts…' in your replies. For instance say:

'I can get out of bed, but I have to wait about 15 minutes after I awake due to my limbs being to stiff first thing in the morning'.

'**I am able to cook a simple meal, however most days I am far and too exhausted and confused and by afternoon I am only able to perhaps make a bowl of cereal.'**