

TOP TIPS WHEN CLAIMING BENEFIT

Number 1

EXPLAIN VARIABILITY

When you are filling in an application or renewal form, don't fill it in as though it is your worst possible day.

If you are having a better part of the day or week when you are being assessed, the assessor or tribunal panel will automatically assume you have exaggerated and class you as someone who is not a credible witness.

You need to explain variability, both throughout the day and the week.

For example, with PIP if you are unable to carry out a descriptor (one of the tasks you are being asked about) at any given point in a 24-hour period, you should be assessed as being unable to do that descriptor for the whole of that day.

In reality, this does not happen during the assessment process and variability is rarely even asked about to that degree, but it is still worth stating, as legally that is how the term "reliably" should be interpreted.

With ESA you need to think about whether you could do a descriptor repeatedly as would be required in a work-related situation.

You might be able to pick up a pint of liquid, for example, but what would happen if you kept trying to do this repeatedly, as may be required on a production line at work?

How quickly would repeating that movement cause your symptoms to worsen? Would you get to a point where you couldn't continue that

INTRODUCING OUR WELFARE RIGHTS ADVISER

Hello! I'm Ann Innes, consultant welfare rights adviser to the ME Association and formerly to Stockport ME Group.

I run a private service to support people throughout the claims process, from benefit entitlement checks, application, preparing for the face-to-face assessment and attending as an advocate, all the way through to mandatory reconsideration and representation at appeal.

I developed Severe M.E. and was completely reliant on personal assistants for every aspect of my care, lost the ability to read and was confined to my bed for three quarters of the day. This degree of impairment continued for around seven to eight years.

It has given me not only understanding of the condition but the ability to ask the right questions around symptoms and functional ability to be able to apply the benefits regulations to M.E.

Here are my SEVEN TOP TIPS that people with ME/CFS should remember when they are claiming benefit.



movement and would have to rest?

◆ The ME Association Guide to Personal Independence Payment for people with M.E. can help you through the application/renewal process:

<https://tinyurl.com/y4xmzrgz>

Number 2

EXPLAIN THE EXTENT OF ANY FATIGUE

Never assume that the assessor knows anything about M.E. The general assumption seems to be that ME is about being visibly tired. I often see "doesn't look tired" on medical assessment reports.

Stay away from the word tired and

focus more on words like "exhaustion" or "debilitating post-exertional fatigue", like the fatigue that accompanies flu for example, perhaps far worse.

"Tired" is a useless word to describe the fatigue that accompanies ME. Explain that it gets worse after minimal physical or cognitive activity.

If you have Severe ME, minimal activity could be getting to the toilet or having a conversation for longer than 15 minutes, so use relevant examples to help explain your symptoms.

If you don't explain, assumptions will be made as to what having ME means and those assumptions will almost always be wrong.

Number 3 FOR PIP EXPLAIN WHY AIDS OR ASSISTANCE WOULD NOT HELP

People with ME are usually given two points for aids, as though the aids will magically enable you to cook a main meal from fresh ingredients or have a shower whenever you feel like it.

So, if aids, or even assistance, wouldn't make a task any easier, you need to explain why this is so.

For PIP you are supposed to be assessed on how you are for over 50% of the time.

If you cannot carry out a task for half the week or more, not even with aids or assistance, you should therefore be assessed as being unable to do that task at all.

Couple this with the correct interpretation of the word "reliably" and many people, particularly those with Severe ME, should be scoring maximum points on many of the descriptors.

Number 4 REMEMBER TO USE THE WORD 'BUT!'

The biggest piece of advice I can give you, for which I must give credit to the "Benefits and Work" website, is to "Remember the word BUT!"

You will probably be asked closed questions by an assessor, such as "do you go on the internet/use your phone to text?"

If I remember back to when my ME was severe, I might have answered:

"Yes, I can read a text, BUT not for the first few hours upon waking as my brainfog is too bad.

"I have to pick my time of day and can only read one or two lines before I start getting electric shock-type sensations in my hand and lose the ability to take in what I'm reading.

"It also exacerbates X, Y, and Z symptoms, to the degree where I wouldn't be able to repeat the activity for the rest of the day."

This is how you need to approach your answers to every task you are asked about. Explain, not only fluctuations in symptom severity and frequency, but also:

- The after-effects of undertaking an activity
- How much rest you need to have had to even attempt it
- If there are parts of the day you cannot do it at all
- How long it takes you to do it (you should score points if it takes you more than twice as long as someone without your health condition)
- How safely you can do something (e.g. risk of falls due to dizziness) and
- Whether you can do something to an acceptable standard (having a shower and letting the water run over you without soaping every part of your body – because that would be too painful or exhausting – is not washing to acceptable standard).

Number 5 ASK FOR PERMISSION TO RECORD YOUR MEDICAL ASSESSMENT

This should be done over the phone as soon as you get your appointment letter – they need at least three working days' notice. For PIP, you will need to take with you two identical pieces of recording equipment (CD or tape, not digital).

Number 6 GET 'RELEVANT' MEDICAL EVIDENCE

Your medical evidence should talk about your functional ability to carry out each of the tasks being assessed for that particular benefit.

A list of diagnoses and medications is not enough.

Make a double telephone appointment with your GP/ME Nurse/consultant/OT if possible and explain how you are affected.

Ask them to be specific about walking distance that you can manage repeat-

edly and reliably in their evidence. If they believe improvements are unlikely, ask them to state that in their evidence as it could be used to argue a longer award.

◆ The MEA Guide to Universal Credit and Employment and Support Allowance for people with ME can help you through the process:

<https://tinyurl.com/y4xhy3am>

Number 7 THINGS THAT MAY COUNT LEGALLY THAT YOU WON'T BE ASKED ABOUT

Two things that I never see assessors asking about during a PIP assessment are prescribed home therapies that you might need assistance with or whether you use any aids to drink.

For example, pacing is a prescribed home therapy for M.E. which many people need support with, such as prompting to take regular rests.

Explain how much support you need with your therapies, as you will be scored points according to the length of time that support takes throughout the week.

With drinking, I see many people with Severe ME who have to use a straw as they feel too weak to pick up a glass.

I also see people whose coordination is affected, and they have to use special mugs with lids on so that, if they drop a drink, they won't spill the contents.

Unfortunately, the reality is that while many of these kind of things should be considered, they rarely, if ever, are.

I never see variability interpreted correctly, nor people with ME scoring points for cognitive tasks or needing help with pacing, for example.

This is in part due to the stigma and/or ignorance still surrounding ME and the guidance that assessors are given by the DWP. But it shouldn't stop you from describing these factors in as much relevant detail as possible.

◆ The MEA Guide to Reconsiderations and Appeals provides information about the options you have and tips on making the most of your appeal.

<https://tinyurl.com/y34ma244>