

LIVING WITH LAM:

GUIDE TO THE PERSONAL INDEPENDENCE PAYMENT (PIP)



PIP is a state benefit that may entitle you to financial help with daily living and mobility costs. PIP is a non-contributory benefit, which means that you don't have to work or have paid national insurance to qualify for it and your income and savings are not considered. You cannot make a new claim for PIP if you are older than your state pension age but if you are already in receipt of it by then it will continue.

PIP has two components: daily living (for help with everyday tasks) and mobility (for help with getting around). Each component can be paid at either a standard or an enhanced rate. You can qualify for either or both components at either rate. Any award is based on your application details and a possible assessment. PIP is awarded for a set period of time and you have to re-apply at the end of each period. PIP may entitle you to help with other benefits you receive (by getting premiums on them) as well as potential council tax reductions. It can also help with transport costs such as a blue badge for parking, reduced or free rail or tube travel and even reduced road tax. You might even be able to use it towards a Motability scheme car or disability scooter.

The benefit is paid because you might need extra help **due to the effects of LAM and not because you have LAM** and an award is never given because of the condition or the drugs that you are taking. This is important because to qualify you will need to demonstrate very clearly what you struggle to do, and the help or assistance you need to perform everyday tasks or to mobilise, all because of the effects of LAM such as breathlessness, tiredness or reduced mobility.

To apply for PIP you first need to contact the DWP (Department of Work and Pensions) by telephone where some basic biographical details will be recorded. You will then be sent an application booklet to complete and to return within a set period of time. The first section of the booklet requires your medical history (but this is the only section that does) and it is recommended that these details are supported by a letter or report from a medical professional. The middle section is where you describe the help you require because of the effects LAM has on you. The final section allows you to explain in detail what LAM is, how it affects you, that LAM is a progressive disease and that you most probably will not improve.

The questions in the middle section assess your ability to perform everyday tasks and how you get around. These are called "activities" and when each one is assessed, points are awarded for the level of help that you need, by using "descriptors". The points range from 0 (no help required) to 8 (cannot perform the activity at all). At the moment, between 8 -11 points in each component (daily living and mobility) will lead to a standard rate award and 12 and above points will lead to an enhanced rate award.

For more in-depth information about "activities" and "descriptors" please follow the link below:

<https://www.citizensadvice.org.uk/Global/PIP%20descriptors.pdf>

(continued over)

The activities that are assessed are:-

DAILY LIVING

- preparing and cooking food
- eating and drinking
- managing your treatments
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating with other people
- reading and understanding written information
- mixing with others
- making decisions about money
- planning a journey or following a route

MOBILITY

- moving around

SUGGESTIONS

To put forward your strongest case, you should always describe your worst day.

- If you don't need any help with a particular activity then say so.
- Stress how much longer (than a normal person) each task takes.
- Do you need to rest during each part of a task?
- Do you de-saturate (your oxygen levels fall) performing daily activities?
- Describe any aids or adaptations you have to help you, e.g. kitchen, bathroom, dressing or mobility aids.
- State who helps with any tasks - relatives as well as carers.
- State your oxygen use (if you use it) for daily activities as well as mobility.
- Explain how a reduced oxygen saturation affects your breathing (breathlessness), causing fatigue and lethargy (slowness) in each task.
- For mobility, state clearly how far you can walk before you have to stop for a rest. Include oxygen as an aid to help you walk (if you use it).

If you haven't been able to complete the application, for any reason, within the DWP deadline always contact them and request an extension.

When you have completed your booklet always photocopy or scan/take photos of it and any attachments before you send it back as the DWP can lose them!

AWAIT YOUR DECISION

Be warned, most first-time applicants are NOT successful or do not get the award hoped for. If this happens to you and you are disappointed, consider applying for a "mandatory reconsideration". If the DWP still do not change their decision you can formally appeal to a tribunal.

ADDITIONAL HELP

The whole process is cumbersome and potentially very stressful. There are ways to optimise your application. Help is at hand both online and in person and we encourage you to consult one of the charities that can help you before completing your application; e.g.:

Citizens Advice have online resources describing all of the information you will need and offer both telephone and face-to-face support. Advisors can even complete your application for you if you need this help and most towns have branches. This help is free of charge. Citizens Advice will direct you to another agency if they are unable to help.

<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/>

Disability Rights UK also have free resources online to help with and explain PIP applications.

<https://www.disabilityrightsuk.org/personal-independence-payment-pip>