

Cystic Fibrosis *our focus*

**Guidance for PIP
Face-to-face assessments**

Introduction

Personal Independence Payment (PIP) is a benefit that helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16 to 64.

PIP is the benefit that has replaced Disability Living Allowance (DLA) for adults making new claims. Everyone on DLA will gradually be asked to claim PIP instead, even if you have an award for 'life' or an 'indefinite' award. If you are invited to claim PIP and choose not to, your DLA will still end.

If you are nearly 16 or over 16, you will be invited to start this process on your own. This means that you can get help from a parent, carer or social worker but all the letters will be addressed to you.

The rate of benefit is decided after an assessment process and depends on how your condition affects you, not the condition itself. The new assessment process looks at an individual's ability to carry out 10 daily living activities and two mobility activities.

“My 19 year old daughter, who has CF, has just made the transition from DLA to PIP. I had heard that this was not necessarily a straightforward thing to do, as the criteria for PIP and DLA are quite different. I decided at the outset to seek the help of the Cystic Fibrosis Trust. My daughter hates discussing CF and the whole process has therefore been quite stressful in that respect, but having expert advice and support made this easier. Overall, the best advice I could pass on is to get expert support – from your CF team or the Cystic Fibrosis Trust. While claiming PIP was stressful and challenging, we were awarded the benefit and it was worth persevering because it's so important to get the right financial support.”

The majority of PIP decisions are made after you have had a face-to-face assessment with a private company approved by the Department for Work and Pensions (DWP).

This guide is intended to help you prepare for that assessment.

We have included parts of official guidance as we believe that there is a framework for these assessments and it helps if you are aware of this.

The DWP publishes official guidance on face-to-face assessments for PIP, which includes the following:

From the PIP assessment guide – DWP guidance as updated on 5 November 2018. (Extracts are numbered)

www.gov.uk/government/publications/personal-independence-payment-assessment-guide-for-assessment-providers.

The assessment for PIP looks at an individual's ability to carry out a series of key everyday activities. The assessment considers the impact of a claimant's health condition or impairment on their functional ability rather than focusing on a particular diagnosis.¹

PIP is not a compensation payment for ill health/disability; it is to help people with the increased costs of daily living in cases of long term ill health or disability.²

This means it is not about the fact you have cystic fibrosis and complications caused by CF, but about the effect that they have on your life, and the things you can and cannot do because of them.

The activities explored during the PIP assessment are:³

Daily living (10 activities):³

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

Mobility (two activities):³

- Planning and following journeys
- Moving around

The guidance also states the following:

Face-to-face consultations may be carried out at a range of locations, including an assessment centre, local healthcare centre or in the claimant's own home.⁴

Health professionals should be prepared to adapt their approach to the needs of the particular claimant, not take a prescriptive approach and ensure that claimants are able to put across the impact of their health condition or impairment in their own words. It is important that claimants feel they have been listened to and that the consultation feels like a genuinely two-way conversation.⁴

The health professional

The health professional (HP) is likely to be an occupational therapist, nurse, physiotherapist, paramedic or doctor.

The guidance states this:

The approach should be relaxed and unhurried, allowing the claimant time and encouraging them to talk about themselves and put across the impact of their health condition or disability in their own words. The claimant and any companion should feel fully involved in the process and feel that the consultation is a genuine two-way process. Summarising back to the claimant what has been said is useful to show active listening and to ensure that key pieces of information have been correctly heard.⁵

The assessment is mostly spent discussing relevant areas and will include questions about hobbies.

Functional examinations may cover one or more of the following:⁶

- Mental functioning
- Vision
- Cardiorespiratory system
- Musculoskeletal system

Before starting a physical examination, the HP must explain the procedure to the claimant, and obtain explicit verbal consent to continue.

Please note that you should not be asked to carry out a peak flow test, and we would advise you refuse this if you are, for safety reasons. Please contact our helpline if you are asked to carry out any peak flow or respiratory function tests in your assessment.

If you wish to record your assessment, you must request this beforehand through Medical Services*. There is guidance as to what is suitable recording equipment.

The assessor should not give you their view on whether you will qualify for the benefit. This is not their decision.

They should end the assessment if it becomes too stressful for you.

***This will be the company in charge of your assessment. It will either be Capita or Atos. Their contact details will be on the letter that was sent out to you with the appointment for your face-to-face assessment.**

How to prepare for your PIP assessment

Please don't feel embarrassed about claiming PIP, or if you are not working currently. PIP is a benefit to help people with the extra costs they have due to their disability or health condition. Daily life with cystic fibrosis can be hard and this is supposed to help you lead a better quality of life and be more independent.

Check through a copy of your PIP claim form if you have one, and make a note of the main areas you have difficulties in, in relation to the 12 'daily living' and 'mobility' activities above.

If you keep a diary or calendar about what you have been struggling with, this can really help. This could cover a 12-month period, but the last three months will be particularly helpful.

Arrange for a friend, family member or professional support worker to go with you. Ask them if they can take notes. They can participate if you want them to.

If you cannot attend on the date given, contact the Medical Services immediately to rearrange.

If you are too poorly to attend an assessment or travel to an assessment centre, you should gather some evidence of this and ask for an assessment at your home (this can take longer to arrange).

Check where the assessment centre is and how to get there. Be realistic, and if you cannot get there let the Medical Services know. You can find out what facilities the centre has by calling them in advance (eg disabled parking spaces or a toilet near the assessment room).

You will be observed and judged as to your ability to do the activities listed above (including planning your journey to the assessment and moving about), so ensure you present how you really are most of the time. Do not try to cover up your breathlessness or fatigue. It is important the assessor sees a realistic picture of the impact daily activities have on you.

You may be asked many questions and may feel like putting on a brave face. Your daily life may be difficult to talk about to a stranger. Please try hard to give as much detail as you can. Think hard about the things that may have become normal for you, but that your friends and family don't have to face. Restrictions caused by your CF may have developed slowly and become the norm, but it's important you identify them so you can tell the assessor. For example, if you go out socially once a month, and have to rest for two days after, then say this specifically rather than simply agreeing that you do regularly socialise. If you take your dog for a walk, but sit on a bench for the duration, make sure you get that across. You may have to be pushy and you may need to elaborate.

The activities listed above are allocated points depending on how difficult they are for you and how much help you need with them.

Taking someone with you

The guidance says:

Claimants have a right to be accompanied to a face-to-face consultation if they so wish. Claimants should be encouraged to bring another person with them to consultations where they would find this helpful – for example, to reassure them or to help them during the consultation. Consultations should predominantly be between the HP and the claimant. However, the companions may play an active role in helping claimants answer questions where the claimant or HP wishes them to do so. HPs should allow a companion to contribute and should record any evidence they provide. This may be particularly important where the claimant has a mental, cognitive or intellectual impairment.⁷

The following points are relevant here:

- The assessor should pick the highest-scoring descriptor that applies to you, but very often if they find out you use an aid to cook, they may not look at whether, in reality, you are still not able to cook most of the time without any assistance. So whilst the use of an aid (eg a perching stool) may mean you get less breathless whilst cooking, make it clear if you are still unable to cook most of the time without any assistance because of pain or fatigue. You may wish to stress how tiredness impacts on safety and therefore your ability to cook.
- The assessor should determine whether you can 'reliably' carry out an activity. This means 'safely', 'to an acceptable standard', 'repeatedly' and 'in a reasonable time'. We can provide more information about this, but if you take twice as long to cook a simple meal using a microwave because you have to stop (due to coughing or needing a rest), then you cannot cook a meal, using a microwave, reliably. If you cannot have a bath 'safely' because of feeling unsafe due to breathlessness and coughing, and need someone to supervise you, then say this at the assessment. Make it clear when you can manage something, but only with assistance. This is the area where most assessors' reports lack detail and understanding.
- You should think about what you have not been able to do for 50% or more of the days in the last three months. This is why a diary can be so useful. Mark down the days where you have needed assistance to prepare a meal, prompting to get your medications ready or have been particularly slow moving around.
- It is important that you state how you are affected by fatigue and breathlessness. Explain if the breathlessness makes you dizzy or unsteady on your feet, and the knock-on effect this has on daily activities. Make sure the assessor understands that fatigue is more than just tiredness, and the ways in which it restricts you.
- If something makes you so anxious that you avoid doing it, then you should say so.
- The assessor may not know much (or possibly anything at all) about cystic fibrosis and you may have to refer to the documents you have provided around preventing infections, issues around cross-infection, specialised diet and the requirement for extra calories and supplemental feeding, associated conditions (osteoporosis, diabetes, liver disease, arthropathy etc), monitoring of your health and things you may actually need a lot of support to do.
- Don't forget to mention the side-effects of your medications if they cause you problems. You may suffer from trembling and jitteriness from certain medications.
- Think carefully about whether you are reminded to order prescriptions, take tablets and do physio. Does someone else wash your nebulisers for you, or would you need someone to if that were an option? You may need help with the regular and onerous cleaning and drying of nebuliser pots (chambers) and their constituent parts, as well as face masks.
- It may be possible that you need help to look after yourself to an acceptable standard, even though the help might not be available (eg if you live alone).

- Your health may have gradually deteriorated over the years and you may have become used to how you manage to carry out certain activities. It may be useful to consult someone who does not have CF and have a chat, perhaps comparing how you look after yourself in the key daily living and mobility activity areas.
- If you feel the assessment has not gone well, try to think why. As soon as you get home, write down what you felt was wrong with the behaviour of the health professional or the procedure.
- If there was a problem, seek advice as soon as you can. There is a complaints procedure. You won't know for up to five weeks how much this assessment has affected the outcome of your PIP claim.

You have the right to view your report, whether your claim is successful or not ('PA4').

We are here to help and support you every step of the way. It can be hard to explain your health problems to someone new and you are likely to be nervous, but do contact us when you want our support and we can help with any disputes and appeals. A little bit of preparation can make everything seem a little easier.

The DWP publishes specific guidance about 'young people', as detailed below:

“Health Professionals (HPs) may need to adapt their approach when assessing young people. Care should be taken, as always, to avoid creating stress or anxiety for the claimant. HPs should be mindful that young people are encouraged to be positive about their health condition or impairment and to focus on what they can do, rather than what they cannot. In addition, young people may have limited experience undertaking many activities unsupervised in an independent environment. The HP should base their assessment on what the young person would be able to do if asked – that is, what they are functionally able to do – not the skills they have or haven't learned.⁸

“Young people may attend a face-to-face consultation with a parent. In these cases, it may be particularly important to distinguish between what a young person can or could do for them self and what the parent does for them as part of their caring role. There may be some activities that have been done for them all of their lives that a young person without a health condition or impairment of the same age may do themselves. There may also be activities that could be carried out by the young person but the parent continues to assume responsibility. It should be emphasised whether the help given is suitable to the role of parent or a carer”⁸.

What does this mean for you?

- If your assessment has not gone well and you felt that you did not or could not get your difficulties across, you can check whether this guidance has been applied.
- It is understandable that you may have painted a more positive picture due to wishing to have a positive outlook, the pressure of the situation or because you wanted to be polite. The HP should take this into consideration but the report may suggest they did not.
- If it is argued afterwards that your parent helps you out of habit rather than necessity, you may have to demonstrate why you need the help you get.
- The guidance may help you argue your case at an appeal, as you may feel that the assessment report from the assessment should not be relied upon and can give reasons why.

If you need help or support with any aspect of your PIP claim, please contact our helpline on helpline@cysticfibrosis.org.uk or 0300 373 1000, opening times are on our website: cysticfibrosis.org.uk/helpline. We're always interested to hear about your experience of your face-to-face assessment, particularly if you feel it didn't go well or you are making a complaint about the assessment.

Updated by Sangeeta Enright, Welfare and Rights Advisor, Cystic Fibrosis Trust – November 2018.

Cystic Fibrosis Trust

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