“A totally degrading experience”

How the PIP system is failing people with cystic fibrosis

Summary version

This summary highlights some key information about the experiences people with cystic fibrosis have had with Personal Independent Payment (PIP). Read the full report: **cysticfibrosis.org.uk/PIP-report**

Introduction

Living with cystic fibrosis (CF) means managing a complex, lifelong condition that affects the entire body. Daily treatments can take up to four hours a day. Alongside regular hospital appointments and the constant management of infections and complications, this places significant demands on people with CF and their families. Despite medical advances, the condition continues to impact almost every aspect of daily life.

The typical family with CF also loses £7,750 per year because of extra spending needed to stay well and having to make different employment decisions due to their CF. Financial support plays a vital role in helping people manage these challenges and maintain their independence. Personal Independence Payment (PIP) is a core part of this.

What is PIP?

PIP is a non-means-tested, non-taxable benefit provided by the Department for Work and Pensions (DWP). It is designed to help with the extra costs of disability and can be claimed from the age of 16. Of the 6,700 people with CF who are aged over 16, almost half receive PIP. It is therefore extremely important that the Government makes sure the PIP system works for people with CF.

Our report

For this report, we heard from 440 people affected by CF who have applied for PIP. This represents more than one tenth of all people with CF who receive PIP. We also heard from 89 CF healthcare professionals who have experience of assisting people with CF with PIP. The findings in this report show that the current PIP process is failing to reflect the realities of living with CF.

PIP fails to reflect the realities of living with CF

People with CF felt they could not fully explain what it is like to live with the condition in the PIP application form. Many found the process so complex that they could not navigate it alone.

And for a large proportion of people with CF, the wrong decision is being made. Four in ten people with CF had their application initially rejected and were only awarded PIP after challenging the decision. The benefits system should offer stability and reassurance to people living with serious health conditions, not add further uncertainty and stress.

The process itself can take a profound toll. Every single CF health professional said the PIP process has an impact on their patient’s mental health. Many respondents described the anxiety of waiting months, and sometimes longer, for decisions. During this time, people spoke of feeling “in limbo”, unable to plan for the future and fearful about how they would cope if their support was removed.

> “I’ve never experienced stress like it, trying to justify how poorly I am or can be to a panel of judges was the scariest thing. I worried day and night up till the appeal.”
>
> Person with CF

> “I had sleepless nights; I was missing treatments because I was so tired from lack of sleep and worrying.”
>
> Person with CF

For people with cystic fibrosis, the stakes are high. PIP does not fund luxuries – it helps people meet the additional costs of living with a serious health condition: food, heating and attending hospital appointments.

A need for reform

This report highlights the need for a benefits system that better recognises the realities of living with cystic fibrosis. By improving understanding of complex and fluctuating conditions and ensuring people receive the right support first time, the Government can help ensure that people with CF are able to live with dignity, independence, and security.

We would like to thank everyone who took the time to contribute to this research. Your voices are vital in helping us advocate for meaningful change. We will keep working with the Government and partners to ensure the benefits system recognises the realities of living with cystic fibrosis and provides the support people need.

We won't stop until CF does.

Key asks

What needs to change?

The PIP system is not working for people with CF. Too many people with CF are denied support, putting their health at risk and making it hard to cover extra essential costs. We want a new, fairer PIP system that works for people with CF.

1. Prioritise specialist medical evidence
PIP decision-makers must put greater weight on evidence from specialist clinical teams, such as CF multidisciplinary teams, rather than brief functional assessments.

2. Ensure all assessors understand CF
Misunderstandings of invisible disabilities and CF-specific challenges – such as fatigue, infection risk, fluctuating health, and daily treatment burdens – can lead to wrong decisions. Training should be mandatory and developed in partnership with Cystic Fibrosis Trust.

3. Stop wasteful and stressful reassessments for lifelong conditions
People with lifelong conditions such as CF should receive longer PIP awards to prevent repeated, stressful reassessments.

4. Build a PIP system that reflects real life with fluctuating conditions
The PIP rules, including the 50% rule, activity descriptors, and informal observations, must be reformed so they properly reflect fluctuating conditions, fatigue, infection risk, and real-world barriers.

5. Recognise the real burden of treatment
Assessments must recognise the cumulative burden of time-consuming treatments and therapies, complex medication regimes, and specialist diets required to manage lifelong conditions like CF.

6. Redesign forms for usability
The PIP claim and review forms should be redesigned with patients, charities, and social workers to be shorter, clearer, and help people explain fluctuating conditions and treatment burdens.

7. Restore trust between assessors and claimants
The PIP system must foster a culture of trust to reduce the adversarial nature of the process.

Key statistics

The wrong decisions

- For over a third of all people with CF currently receiving PIP, the right decision was not made the first time.
- Just 5% of CF health professionals think the correct PIP decision is normally made the first time.
- Two-thirds of CF health professionals think PIP awards are usually too short.

Taking a toll on health

- 9 in 10 people with CF said waiting for their PIP decision affected their mental health.
- Every single CF health professional said the PIP process negatively affects their patients' mental health.
- 8 in 10 CF health professionals said the PIP process affects their patients' physical health.

Struggling to meet basic needs

Half of people with CF who are receiving PIP said they found it difficult to get by financially in the last month.

If people with CF lost access to PIP:

- 1 in 2 would have to cut back on food
- 1 in 4 would have to cut back on heating
- 1 in 5 would lose their car
- 1 in 10 would have to cut back on hospital appointments.

Clashing with the reality of life with CF

- Only 1 in 10 people with CF felt they could fully explain what life with the condition is really like on their PIP forms.
- Two-thirds of people with CF said assessors didn't understand how much CF symptoms can vary, and 95% of CF health professionals agreed that fluctuating health is often ignored.
- A third of CF health professionals believe PIP assessors rely too much on informal observations.
- 6 in 10 said they couldn't have filled out the PIP forms if they hadn't had help.

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