Cystic Fibrosis Trust

"A totally degrading experience"

How the PIP system is failing people with cystic fibrosis

Uniting for a life unlimited

“A totally degrading experience”

How the PIP system is failing people with cystic fibrosis

Contents

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Acknowledgements

We would like to thank the CF community who took the time to share their story with us; without you, this report would not have been possible. Thanks to you, we’re able to use our findings to continue to lobby the Government and campaign for long-lasting and meaningful change. A huge thank you to the CF community for your ongoing continued support, and to anyone who has generously donated to Cystic Fibrosis Trust.

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Foreword

Living with cystic fibrosis (CF) means managing a complex, lifelong condition that affects multiple parts of the 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 individuals and families.

Despite medical advances, the condition continues to shape almost every aspect of daily life. Financial support plays a vital role in helping people manage these challenges and maintain their independence.

Yet the findings in this report show that the current PIP process is failing to reflect the realities of living with CF. Nine in ten 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, with more than six in ten saying they could not complete their application without help.

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. Nearly all CF health professionals we surveyed (96%) believe the PIP system has a moderate or significant negative impact on their patients' 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.

For people with CF, the stakes are high. PIP does not fund luxuries – it helps people meet the additional costs of living with a serious health condition.

Without it:

- half of our respondents would be forced to cut back on food
- a quarter would have to cut back on heating
- others would lose access to their car or struggle to attend hospital appointments.

This report highlights the need for a benefits system that better recognises the realities of living with CF. 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.

I am continually struck by the resilience and determination of the CF community. Despite the daily challenges of managing a demanding condition, people with CF and their families continue to share their experiences to help drive improvements for others.

I would like to thank everyone in the CF community 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 CF and provides the support people need.

We won't stop until CF does.

David Ramsden
Chief Executive, Cystic Fibrosis Trust

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.

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.

For more specific recommendations, please refer to **Our asks in full** (page 33).

About cystic fibrosis

Who is Cystic Fibrosis Trust?

Cystic Fibrosis Trust is the only UK-wide charity uniting people to stop cystic fibrosis. We fund vital research, improve care, speak out, and race towards effective treatments for all. We won't stop until everyone with cystic fibrosis can live without limits.

What is cystic fibrosis?

Cystic fibrosis (CF) is a life-limiting genetic condition. It impacts physical and mental health and has no cure, affecting over 11,300 people in the UK. There are approximately 9,500 people in England living with CF, 1,000 in Scotland, and 500 in each of Wales and Northern Ireland. Since 2015, around 250–300 people have been diagnosed with CF every year.[1] In 2024, the median age of death for those with CF was just 42 years old.

CF affects people with the condition in many ways throughout their lives. The condition primarily affects the lungs and digestive system, causing them to become clogged with thick, sticky mucus. It also causes many comorbidities:

- one-third of adults with CF also have CF diabetes (a specific form of diabetes)
- a quarter have liver disease
- one-tenth have urinary incontinence (involuntary loss of bladder control).

Those living with CF cannot meet each other face-to-face due to the risk of cross-infection.

Living with CF demands an incredibly high burden of treatment, which takes at least two to five hours every day. Medication, physiotherapy, and general health all must be considered for people with CF when planning even simple activities. People with CF take an average of 34 tablets daily.

The cost of living with CF

The typical family with CF loses £7,753 per year because of necessary extra spending to stay well and having to make different employment decisions due to managing their CF.[2] 35% of people with CF have lost or left a job because of their health.[3]

This is equivalent to £646 per month in extra costs and lost income. These expenses include transport to medical appointments, treatments, special dietary requirements, and escalated energy bills. Every month, compared to someone without CF, the average adult with CF spends an extra £68 on food, £30 on energy, and £25 on appointment-related costs, such as travel. For parents of children with CF, appointment-related costs rise to £42 per month.[4]

Families with CF are also far more likely to experience financial hardship than the general UK population. Nearly a quarter (24%) of adults with CF, and over a third (35%) of parents of children with CF, report constant struggles to meet their monthly bills. This starkly contrasts with 17% of the overall UK households facing similar challenges. Our recent Your Life and CF report (2025) revealed that 40% of people with CF have had to prioritise one essential over another, with 20% worried about losing their housing and 90% worried about the future.[5]

What is PIP?

Personal Independence Payment (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.

[1] UK Cystic Fibrosis Registry 2024
[2] The Cost of Cystic Fibrosis, adjusted for compound inflation until 2026
[3] Your Life and CF, 2025
[4] The Cost of Cystic Fibrosis, adjusted for compound inflation until 2026
[5] Your Life and CF, 2025

People can claim PIP in England, Northern Ireland and Wales. In Scotland, the equivalent benefit is Adult Disability Payment.

PIP has two components: the daily living component and the mobility component. Each component can be paid at either a standard or enhanced rate and people may qualify for one component but not the other. People can qualify for both. This means people receiving PIP can get between £121.20 and £778.40 every four weeks, depending on the level of support they are considered to need, and the rate and components that are awarded.

CF and PIP

There are more than 11,300 people with CF in the UK. 6,700 of these are aged over 16, the age at which you can claim PIP from. Government data shows us that almost half of this group (46%) receive PIP. It is therefore extremely important that the Government makes sure the PIP system works for people with CF.

How do people access PIP?

To apply for PIP, people must send an application form to the DWP. In rare cases, the DWP may make a decision based on the form and supporting evidence alone. However, in most cases, people also have to undergo an assessment carried out by a health professional working on behalf of a private assessment provider.

After the assessment, the assessment provider sends a report to the DWP recommending:

- whether the person should be awarded PIP
- what rate they should be awarded
- how long the award should last

A DWP case manager then makes a decision. In most cases, their decision aligns with the assessment provider's recommendation.

If someone is declined PIP, or they are unhappy with the award they receive because they think it is too low or too short, they can appeal the decision.

The first step to appeal is to request mandatory reconsideration. If they are still unhappy after this, they can appeal through an independent tribunal.

Nationally, across all conditions, around two-thirds of people who are initially refused PIP and then appeal to an independent tribunal have the decision overturned in their favour.[6] However, many people do not appeal because of the stress involved and the possibility that an existing award could be reduced or shortened.

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[6] Personal Independence Payment statistics to April 2025 – GOV.UK

Methodology

This report presents data from a Cystic Fibrosis Trust survey of 440 people affected by CF who have applied for PIP, including both people living with CF and those supporting them, such as parents, partners and carers, who helped them to apply or applied on their behalf. This response represents more than 1 in 10 (14%) of all people with CF in receipt of PIP as of October 2025, giving us a rich insight into the realities of accessing PIP while living with CF.

The survey ran from 3–27 February 2026 and was promoted by the Trust via email, social media, through relationships held with the community by our support team, and through coalitions and groups of CF healthcare professionals.

It included questions on experience of the PIP process and demographic information. The Trust's Policy and Public Affairs team analysed the survey responses we received, using both a quantitative analysis of the statistics and thematic analysis of comments.

We also conducted a complementary survey of 89 CF healthcare professionals who have experience of assisting patients with PIP, including 34 nurses, 18 social workers, 15 consultants, 9 physiotherapists, 8 dietitians, 4 psychologists and 1 occupational therapist. These responses provide additional insight into the difficulties people with CF face in applying for PIP.

Finally, the section **Closing remarks: My thoughts after 10 years supporting people with CF to access PIP** (page 32) provides insight from the Trust's Welfare and Rights Advisor, Sangeeta Enright. With over a decade of experience and a 99% success rate supporting people with CF to appeal their PIP decisions, Sangeeta has firsthand experience of the challenges facing people with CF in the PIP process. Her experience adds to the wealth of insight we have gathered from people with CF and CF healthcare professionals through our surveys.

Topline results

Findings from our surveys, alongside insights from years supporting people with CF to access PIP, reveal a process that is challenging from the outset and fails to reflect the realities of living with CF. It places a profound strain on both physical and mental health, with many people experiencing anxiety and going without essentials such as food and heating while they wait for their PIP decision.

The vast majority of people with CF felt they couldn't fully explain what it is like to live with CF through the PIP application forms. Many found the process too complex to navigate alone. And too often, the system wrongly denies people with CF the support they need – and are entitled to.

Recommendation: Design a new PIP system that better supports people with lifelong conditions, while ensuring reforms do not make it harder for people with CF to qualify.

People with CF are not receiving the right decisions

People with CF face a huge range of difficulties in the PIP process. Assessors do not understand the fluctuating nature of their condition and may ask irrelevant questions. As a result, too many people with CF do not receive the right decision the first time.

Our research found that 38% of people with CF who currently receive PIP were initially given the wrong decision and were only awarded PIP after mandatory reconsideration or appeal.

Just 5% of CF health professionals think the correct PIP decision is usually made the first time. The vast majority (87%) think the correct PIP decision is usually only reached after mandatory reconsideration or appeal, while 7% think the correct decision is never made, either because claims are refused or because the award is too low or short.

We also know that many people with CF find the PIP process so stressful and demoralising that they don't appeal. This suggests the true number of incorrect initial decisions is even higher than reported.

The fact that so many people with CF are initially declined PIP is very concerning. It is also a waste of DWP time and resources. Change is needed to create a PIP system that works for people with CF so that the right decisions are made the first time.

> "[I had a] patient with severe haemoptysis [coughing up large amounts of blood], unable to work and facing lung transplant, not awarded anything."
>
> CF doctor

> "The disputes and tribunals I have attended have all had the decision to not award PIP reversed which indicates how poor the process is."
>
> CF nurse

> "One man with CF had severe depression and anxiety, regularly self-harmed, and was only scored 1. Following mandatory reconsideration this did not change. At tribunal he was awarded standard care daily living, with the acknowledgement that this should not have needed to go to tribunal."
>
> CF social worker

The PIP process has a significant impact on the physical and mental health of people with CF

The most consistent theme across responses from people with CF was sustained anxiety caused by waiting for decisions, reassessments, or appeal outcomes. Many described constant worry about whether they would continue to receive support and how they would cope financially if it was removed.

- 9 in 10 people with CF said waiting for their PIP decision affected their mental health, with 1 in 2 saying the impact was significant.
- Every single health professional we surveyed said they think the PIP process negatively affects their patients' mental health, with 6 out of 10 (61%) describing the impact as significant.

> "I was so anxious. I felt like I was frozen in time and couldn't think about the future as I was just waiting and waiting for my PIP appeal date. It took over a year from when I first lodged my appeal to when I received a hearing date and during that time I felt in limbo and couldn't relax." – person with CF

> "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

Uncertainty often lasted for months – in some cases over a year – leaving people feeling "in limbo", unable to plan for the future or feel secure. Our research found that over 1 in 2 (55%) people had to wait at least seven months to receive a decision from the point of first applying, and 1 in 5 (18%) had to wait over 13 months. For those who went to appeal, this rose to 3 in 4 (74%) and 1 in 3 (37%) respectively. On top of managing a progressive, lifelong condition like CF, these delays were described as deeply distressing and, at times, overwhelming.

> "We appealed and are still waiting for a hearing over a year later!" – parent of son with CF

The process itself was frequently experienced as stressful and adversarial. Many felt they had to prove they were ill enough to qualify, often to assessors with limited understanding of CF. This led to feelings of being disbelieved, judged, or treated "like a fraud", alongside experiences of imposter syndrome and self-doubt.

> "The lack of belief makes you experience a lot of imposter syndrome and feel as though you aren't 'disabled enough' to receive PIP." – person with CF

> "Feeling trapped and treated like a liar." – person with CF

People said they found it emotionally exhausting and dehumanising to have their condition scrutinised in detail or to be reduced to how they appear on a "good day". Repeated reassessments and appeals, including tribunals, compounded this stress and eroded trust in the system.

> "I have had to take more than one benefit appeal to tribunal and each time it has drained me and had a negative effect on my health and wellbeing. I also feel I live in a constant state of vigilance where the DWP are concerned." – person with CF

> "It was exhausting having to go through the arduous process of mandatory reconsideration, appealing and then the tribunal. It felt as though I wasn't being listened to at each point and the months of waiting between each was anxiety inducing and stressful." – person with CF

Recommendation: Instil a culture of trust in the PIP system to reduce the adversarial nature of the process.

Importantly, respondents highlighted that this psychological strain often had direct physical consequences. 8 in 10 (82%) CF health professionals said they think the PIP process affects their patients' physical health, with 1 in 5 (21%) saying the impact is significant. Increased stress and anxiety were linked to worsening symptoms, including fatigue, sleep disruption, chest infections, and even hospitalisations. Some people reported being unable to maintain treatment routines or daily functioning due to the mental burden of the process.

> "I had sleepless nights; I was missing treatments because I was so tired from lack of sleep and worrying." – person with CF

“The worry significantly affected their health condition – it took a huge decline – and they are still continuing to regain their base level of health prior to appealing.” – parent of child with CF

Financial fear was a key driver of distress. Many described acute anxiety about being unable to afford food, heating, rent, or travel to hospital appointments – particularly those unable to work or already working at their limit due to their condition. Many reported cutting back on essentials while waiting for their PIP decision, risking further deterioration in their health.

“I am constantly worried about my finances and how I will afford to live.” – person with CF

“Fear of not being able to pay basic bills, fear of being forced to work and my body breaking down.” – person with CF

“I was left with no support for 6 months, in this time I had to ration food, electricity, water, and general day to day expenses in order to get by.” – person with CF

“Financial limbo during the waiting period forced me to think twice about basic but necessary costs such as heating, nutrition, transport, and rest. These are not optional extras for someone with CF; they are part of managing the condition.” – person with CF

Recommendation: Reduce PIP decision times to reduce the huge impact on mental and physical health and ensure people get their PIP payments faster.

Recommendation: Pay claimants a reduced rate of PIP while they wait for their appeal, and do not require repayment if the appeal is unsuccessful.

People with CF find the process too stressful to appeal

A significant proportion of people with CF (38%) who currently receive PIP were only awarded it after mandatory reconsideration or appeal. This tells us that if a person with CF applying for PIP is initially declined, they have a high chance of their decision being overturned at appeal.

Yet many people with CF don’t take their application any further. The stress and complexity of the process prevent them from challenging incorrect decisions.

Two-thirds (67%) of CF health professionals think most of their patients who have their initial PIP application declined do not go on to appeal if they are rejected at mandatory reconsideration. They consistently identified the process itself as the primary barrier to appeal, with patients believing it to be too time-consuming and stressful, alongside a widespread perception that appealing would be pointless. We know that this is not the case, especially with the assistance of a social worker or benefits advisor. Our own Welfare and Rights Advisor has been successful in helping to overturn over 99% of PIP appeal cases she has assisted in.

“They don’t feel there is any point [appealing] and they can’t face the process.” – Fiona Dowdall, Co-chair of UK Psychosocial Professionals in CF Group (UKPPCF)

“Sadly, [my daughter] has never felt strong enough to reapply. She now has even more complications but doesn’t have the energy to fight.” – parent of daughter with CF

> “Despite recommendations to pursue mandatory appeals, some patients have declined due to apprehension about facing additional questioning and feeling that their accounts are not being fully accepted.” – CF social worker

Recommendation: Ensure the PIP process is open, transparent, and built on trust so that people who are wrongly denied, or given an inadequate award, feel able to appeal.

Currently, there is no requirement for people to receive their PIP assessment report which could reveal where incorrect decisions have been made and could help give people the confidence to appeal.

Recommendation: Provide PIP assessments reports automatically following people’s assessments so they can identify inaccuracies and challenge decisions where they need to.

Additionally, PIP assessments can be recorded but currently someone has to know to request this and for the request to be accepted. We believe all assessments should be recorded by default. This would hold assessors to account and make settling disputes easier.

Recommendation: Record PIP assessments by default unless the claimant chooses to opt out.

PIP awards do not cover the cost of living with CF for many

Living with CF costs people with CF on average an extra £7,753 (£646 per month) every year just to stay well. These costs include travelling for extra medical appointments, having special dietary requirements, having high energy bills, and having to make different employment decisions.[6]

PIP rates range between £121.20 and £778.40 every four weeks, depending on whether recipients qualify for both the daily living and mobility components and if they receive standard or enhanced rates.

For most people with CF, PIP does not cover the extra costs of living with the condition. Less than half of people with CF who receive PIP (44%) qualify for the highest rate, leaving the majority without full support. Many experience even higher costs: a quarter of people with CF lose £1,254 each month as a result of CF – well above the maximum PIP award.

Half of people with CF who receive PIP reported financial difficulty in the last month, even with the benefit. The community also highlighted that the PIP assessment doesn’t account for condition-related costs, despite PIP’s purpose.

> “I also feel frustrated that the questions often do not account for the variability of my CF or the additional costs that I often incur as a result of my disability.” – person with CF

> “[It] does not take into account the financial burden of having a chronic health condition – travel expenses, increased food budget, prescription costs, increased travel insurance.” – CF nurse

> “The thing that frustrates me most about PIP is that it claims to be a benefit to help with the cost of being chronically ill and yet nowhere in those forms does it ask about your expenditure.” – person with CF

Recommendation: Commit to a minimum PIP rate which is aligned to actual average disability costs to ensure the costs of disability are covered. Benchmark PIP rates against external evidence, such as CF-specific costs.

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[7] The Cost of Cystic Fibrosis, adjusted for compound inflation until 2026

PIP rates are typically increased each April using the previous September's Consumer Prices Index (CPI). However, households affected by long-term conditions like CF are more likely to experience higher inflation than the general population. This is because they spend a higher proportion of their income on essentials, such as food and energy, which are often the most affected by inflation.

Recommendation: Increase PIP rates annually by more than the previous September's Consumer Price Index (CPI), reflecting the higher inflation experienced by disabled households.

PIP awards are not long enough

Even when people with CF are awarded PIP without having to pursue mandatory reconsideration or appealing, many receive awards that are too short.

- Almost 1 in 2 (47%) people with CF were given awards of less than five years.
- 2 in 3 (68%) CF health professionals said they thought PIP awards are "usually" too short.

Given CF is a lifelong, genetic, and progressive condition, there are not likely to be significant changes in the general day-to-day management and support for a person with CF's condition, such as diet, therapies, and daily living activities. If someone's circumstances change in a way that could materially change the rate of their award, they already have a duty to notify the DWP and prompt a review.

> "The conditions my son has are lifelong and I can't understand why we don't have a light touch review." – parent of son with CF

> "Having to go through such a vigorous process every 2.5-ish years, as someone who struggles daily with severe anxiety, is awful." – person with CF

It can take many months, or even over a year, to be awarded PIP, longer still if an appeal is needed. This means that by the time someone receives a three-year award, for example, it may only be a year until their next review, as payments are backdated to the original claim date and reviews may begin a year before the recipient's PIP award is due to expire. Many people with CF described feeling like they are in a revolving door, constantly collecting evidence, attending assessments, appealing decisions, and starting the process again. They have no certainty that they will continue to receive PIP, despite knowing for certain that they will have CF for the rest of their lives.

If PIP is withdrawn at review, payments stop immediately, leaving no time to adjust financially or make alternative arrangements for essential living costs.

Recommendation: Award longer PIP awards to people with lifelong conditions such as CF to prevent repeated, stressful reassessments.

Recommendation: Pay claimants a reduced rate of PIP while they wait for their appeal, and do not require repayment if the appeal is unsuccessful.

Without PIP, people with CF would struggle to meet basic living needs

We asked people with CF what they would have to go without, or cut back on, if they didn't receive PIP. The responses show that PIP does not fund optional extras. It enables people with CF to meet the basic costs of their condition, access healthcare, remain independent, and protect their health and ability to work. PIP acts as an essential income floor, not supplementary support. Losing access to PIP risks causing material deprivation and worsening health.

- 1 in 2 (53%) said they would have to cut back on food.
- 1 in 4 (26%) said they would have to cut back on heating.
- 1 in 5 (18%) said they would lose their car.
- 1 in 10 (8%) said they would have to cut back on hospital appointments.

These figures come from responses to an open-ended question. We therefore believe it is likely that even more people are cutting back on these essentials than the figures show, as many respondents may not have listed everything they would be forced to reduce.

Without PIP, many would struggle to meet basic living needs. They would have to cut back on essentials, including things they need to stay well. People most often told us they would reduce spending on food, particularly the high-calorie, nutritious diets necessary to maintain good health with CF.

They also said they would cut back on heating, electricity, and other household bills, which are essential for managing CF. Having CF can increase the amount of calories you need to eat by up to 200%. For some, losing PIP would risk housing instability or force them to move back in with family. Respondents repeatedly described facing impossible choices: choosing between heating and eating, or medication and petrol.

> "I would struggle to buy the food I need, have to have the heating on less to be careful of bills. Essentially I would exist rather than live." – person with CF

> "Everything, I wouldn't be able to afford my prescriptions, food shopping as someone with cystic fibrosis has a very high fat/calories diet, fuel as I have many hospital, psychologist and physiotherapy appointments each week. So unfortunately I wouldn't be able to attend them. Heating and electrical bills would be near impossible to afford." – person with CF

> "I wouldn't be able to afford replacing clothes I have spoiled due to incontinence and illness at all." – person with CF

Access to healthcare is another major concern. Many people rely on PIP to cover transport costs for their many hospital appointments, which can involve long journeys, as well as parking and public transport. Others use it to cover treatments and health-related costs not fully funded by the NHS, including additional supplements, physiotherapy, gym memberships, or specialist items. Without PIP, people told us they would miss appointments, reduce treatments, or ration heating and nutrition, which would directly worsen their health and increase hospital admissions.

> "If I did not receive PIP, I would have to cut back on things that are essential to managing my CF, not luxuries. The first areas affected would be medication, heating, nutrition, transport, and rest. I would find it difficult to find additional money to pay for essential prescription medication. I would be more likely to ration heating, even though keeping warm is important for my respiratory health. I would also have to be more restrictive with food choices, despite the fact that maintaining blood sugar, weight, calorie intake, and good nutrition is a key part of managing CF and CF-related diabetes." – person with CF

Loss of mobility and independence was also a key theme, particularly for those relying on a car to reduce infection risk from public transport or using a Motability vehicle.

1 in 3 (34%) people with CF who receive PIP lease a vehicle under the Motability Scheme. People only qualify for the Motability Scheme because they have been found to have high mobility needs. They use part of their PIP to lease a vehicle. Two-thirds (65%) of people with CF currently leasing a vehicle told us they also made additional payments to get a vehicle that meets their mobility needs.

Without a vehicle, many said they would struggle to get to work, attend hospital appointments, or maintain social connections, leading to isolation and reduced quality of life.

> "I would have no Motability car because I wouldn't be able to afford it anymore. I would lose my independence to a great degree with no means of travel... I couldn't get to hospital appointments or [have the] freedom to travel without the assistance from family or friends." – person with CF

> "I would probably be unable to continue working. My hospital appointments would be impacted as I would not be able to afford the petrol/electric to get there."
> – person with CF

Respondents emphasised that they cannot simply work more to replace lost income due to fatigue, treatment burden, and fluctuating health. For many, PIP makes it possible for them to work and prevents them falling into deep poverty.

PIP is not linked to whether someone is in work. It is designed to cover the extra costs of living with a long-term condition. Three-quarters (73%) of people with CF who are over 18 and receive PIP are currently in work or full-time education, challenging common narratives about benefits and work. However, almost half of this group (44%) said they had found it "fairly difficult" or "very difficult" to get by financially in the previous month. A tenth (11%) of people with CF are unable to work due to their health.

Overall, responses show that PIP is not funding luxuries. It supports health, independence, ability to work, and dignity. Removing it would not mean small lifestyle changes; it would mean people cannot meet basic needs while managing a serious, lifelong condition without a cure.

Some people with CF who have been denied PIP are already living this reality.

For example, this CF social worker revealed how losing PIP can have catastrophic results:

> "One of our patients lost entitlement following a review... [they] consequently lost significant amounts of weight and came into hospital for supplementary feeding as a result of not being able to afford to buy food." – CF social worker

The journey through PIP: difficulties at every turn

We have outlined the significant impact the PIP process has on people with CF, the essentials they would be forced to go without and the reality that many people with CF are not receiving the right decision. We are now going to go through the PIP process chronologically and outline the specific challenges people with CF are facing at each point and where we, and the CF community, need to see change.

Filling out the forms

The first stage of the PIP process is filling out a claim form. What sounds like a simple task is riddled with challenges for people with CF.

Getting a PIP claim form in the first place is difficult

The difficulties begin from the moment people try to start the process.

A claim for PIP must usually be initiated by a phone call to the DWP, although in a small number of areas you can start the process online. This process allows the DWP to collect information about the claimant to determine whether they meet basic entitlement conditions, such as age and residence. If these are met, the claimant is then sent a PIP claim form to fill out.

However, only 1 in 3 (36%) CF health professionals think the process for starting a claim for PIP is clear and simple,[8] with one CF social worker telling us there are long waiting times when calling to request a claim form. To reduce this, several health professionals said that everyone should have the option to begin a claim either online or via the phone.

This process can be particularly challenging for younger people with CF who are still at school. One CF social worker explained that new claimants may have to call the DWP during school hours and that parents aren't always allowed to speak on their behalf.

> "Having to make a phone call to start a claim is outdated and unnecessary." – Occupational therapist

Recommendation: Offer claimants the option to start a PIP claim online.

People do not have enough time to fill out the form

Once the claim has been started, people are then given one month to fill out and return a PIP claim form. Forms are usually sent by post, which takes time. Once postal delivery and return time are factored in, people often have less than three weeks to complete the form. This is not long enough to complete a lengthy form alongside the demands of living with a long-term condition.

People can request an extension, and in our experience these are normally granted. However, this is another step people have to take and one that many are not aware of. It would be simpler if everyone had the choice to complete their form online or by post, allowing more time and flexibility.

Recommendation: Allow people to choose whether to receive their PIP claim form online or by post.

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[8] 'Don't knows' excluded.

PIP forms are difficult to fill out

Many people with CF find PIP forms difficult to fill out because they are unclear, repetitive, too long, and don't ask questions that are relevant to CF.

> "The questions are very difficult to answer and we needed a lot of support to complete it." – parent of child with CF

> "[PIP forms are] far too long, some patients/parents don't have the ability to understand the questions and are put off by the form." – CF nurse

Because of the complexity of the forms, many people require professional assistance to be able to fill them out. Our research found:

- Nearly 7 out of 10 (67%) CF health professionals are frequently asked to help patients fill in PIP application forms.
- 6 in 10 (61%) members of the CF community said they could not have filled out their PIP claim or review forms without help. Only 3% said they had no help filling out their form and found filling it in easy.
- Most (72%) CF health professionals think PIP claim forms are not user-friendly and 2 out of 3 (67%) think the same about PIP review forms.

It should not be necessary for the majority of people with CF claiming PIP to require assistance from social workers and benefits advisors. PIP forms should be made simpler, so fewer people require help. They should also signpost to organisations that can provide support.

> "More guidance, clearer questions, and access to step-by-step support from the beginning would make a big difference." – parent of a child with CF

Recommendation: Work with patient charities and social workers to redesign PIP claim and review forms so they are clearer, shorter, less repetitive, and more relevant to people with long-term conditions such as CF.

Recommendation: Include signposting on PIP claim and review forms to organisations that can help them complete the form.

PIP claim forms do not allow people to accurately explain how CF affects them

Only 12% of people with CF who took part in our research felt they could fully explain what it's like to live with the condition on their PIP forms.Many said the questions on the forms were not relevant to their condition, too generic, and did not allow them to explain how CF affects their life.

> "Many [of the questions on the forms] do not relate to the difficulties that CF sufferers deal with on a daily basis." – parent of child with CF

> "I felt the questions were too generic for someone suffering from CF."
> – person with CF

Some commented that yes or no questions do not account for the fluctuating nature of CF.

> [When asked what could be improved] "To have different forms for different disabilities with more options than yes/no boxes." – parent of child with CF

> "The form asked questions that were not relevant to CF but omitted aspects which are. It makes limited allowance for seasonal variation in health and symptoms. We completed it after school summer holidays and a period of rest, so symptoms were at their very best. The form and assessment doesn't make it straight forward to detail this." – parent of daughter with CF

Although PIP claim forms state that claimants should explain how their condition varies, this guidance is often overlooked in a lengthy form. People should be reminded of this throughout.

Recommendation: Remind people clearly throughout PIP forms that, if their condition fluctuates, they should describe how they experience most days and how this affects their ability to complete tasks.

People with CF don't know they can provide supporting evidence

People can submit supporting evidence with their PIP claim form or at a later date. This can include reports or letters from medical professionals; reports, statements or diaries from carers or family members; medical test results; or a list of prescribed medicine.

We know from our Welfare and Rights Advisor that medical evidence is crucial to whether someone with CF is awarded PIP, given that the complexities of CF can be difficult for assessors to understand. People with CF in the UK have access to multidisciplinary teams of CF consultants, dietitians, social workers,[9] psychologists, and nurses, who all have a specialist knowledge of their CF and could provide medical evidence.

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[9] CF centres in Scotland do not have social workers.

However, we found that only 1 in 10 (13%) CF health professionals think most applicants are aware of the types of supporting evidence they can provide. And for people with CF who have applied but have never been awarded PIP:

- 1 in 5 (17%) did not provide medical evidence with their last PIP application
- 1 in 10 (9%) said they weren't aware they could provide medical evidence with their application.

These individuals may have received a different outcome had they known to provide evidence. People who had applied for but never received PIP were nine times more likely than those currently receiving PIP to be unaware that medical evidence could be submitted.

Recommendation: Explain clearly on PIP forms that people can submit supporting evidence and outline the types of evidence that can be provided.

Recommendation: Provide templates to help people collect supporting evidence from health professionals, carers, or family members.

PIP assessors should do more to collect the medical evidence they need

PIP claim forms allow people to list the contact details of up to three health professionals. This causes people to believe assessors will contact these professionals directly for medical evidence. In practice, if no evidence is provided, assessors are not required to seek it and rarely do so even if contact details are given. This creates a gap between expectation and reality.

Recommendation: Encourage claimants to submit medical evidence on PIP forms. Where claimants do not provide evidence, proactively seek evidence from named health professionals and contact claimants if further information is required.

DWP decision makers don't give enough consideration to medical evidence

Even where medical evidence is provided, PIP decision-makers can place greater importance on the report from the assessor, despite this only capturing a snapshot of a claimant's experience. The assessment may not reflect how a condition affects someone over time, particularly for fluctuating conditions such as CF. In contrast, medical evidence can provide a much more detailed picture of how someone's condition or disability has affected them over a longer period.

> "Medical evidence was ignored and considered irrelevant. The assumptions the assessor made on the home visit seemed to trump everything." – parent of child with CF

We believe this contributes to why so many decisions are overturned at tribunals, where strong supporting medical evidence is considered more thoroughly.

Recommendation: Give greater weight to medical evidence from specialist teams, such as CF multidisciplinary teams (MDTs), than to evidence gathered during assessments.

Recommendation: Provide PIP assessment reports automatically to claimants following their assessment so they can identify inaccuracies and challenge decisions where necessary.

Getting evidence from health professionals is difficult

Claimants can struggle to collect evidence from health professionals. Of those with CF who didn't provide medical evidence with their last PIP application, over a quarter (27%) said they tried to get evidence but couldn't.

The most common reason (42%) given by CF health professionals was being unable to meet deadlines. Many believed that supporting evidence had to be submitted at the same time as the claim form. In reality, evidence can be submitted separately, but this is not always clearly understood. There is no clear deadline for the submission of supporting evidence, which perhaps adds to confusion.

Recommendation: Make it clear on PIP claim forms that supporting evidence can be submitted after the claim form, clearly state the deadline for submitting additional evidence, and allow deadlines to be extended when needed.

People with CF do not know what information they need to provide

People often include information on their applications that is not relevant to whether they will be awarded PIP, suggesting a lack of clarity about how decisions are made. Only 15% of CF health professionals think PIP claim and review forms make it clear what sort of information is relevant.[10]

> "I think a qualifying criteria matrix should be included and people should have to include evidence to demonstrate how they meet the criteria." - CF nurse

> "It would be beneficial for the form to provide further details on what is likely to meet criteria and what is not likely to meet criteria. The PIP claims are very different to DLA forms which most parents/young people are used to." - CF nurse

Recommendation: Include the descriptors used to assess eligibility on PIP claim and review forms so claimants understand what decision-makers can and cannot take into account.

Many people with CF are also often shocked that time spent on treatments only counts if they require help to perform them, and that the criteria focuses on ability to perform tasks rather than the extra costs associated with living with the condition. This highlights a wider issue with how the assessment criteria reflect lived experience, which is explored further in the section **The PIP assessment criteria do not capture the reality of living with CF** (page 26).

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[10] 'Don't knows' excluded.

Assessments

After submitting a PIP claim form, a minority of claimants receive a decision made based on their form and the supporting evidence. However, most are asked to attend an assessment. This could be face-to-face, by video call, or over the telephone. As with the forms, people with CF encounter significant challenges at this stage.

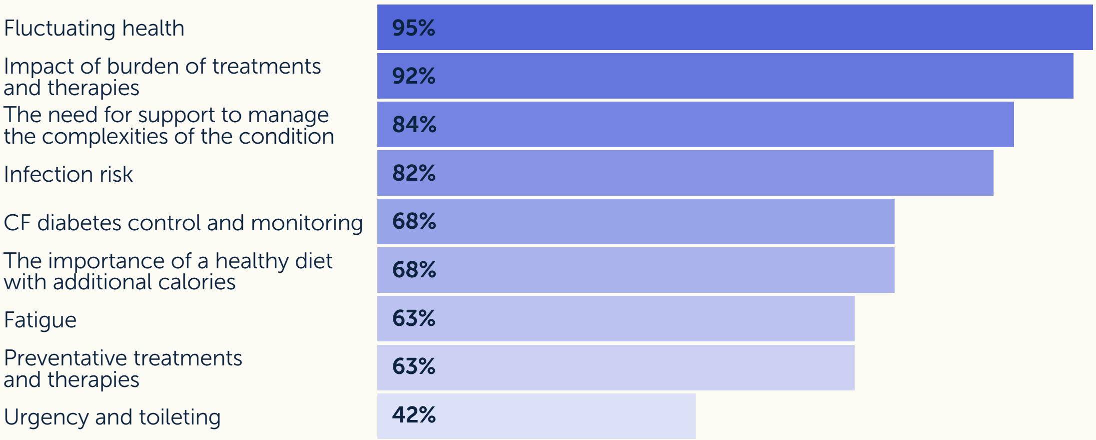
Assessors do not understand CF

The assessors often have a poor knowledge of CF. This means they make incorrect judgements about what life is like with the condition.

The vast majority of CF health professionals felt that assessors didn't take into account essential aspects of life with CF, including:

- the fluctuating nature of the condition
- infection risk
- the impact of having to do treatments and therapies, including physiotherapy, exercise, and regular appointments with their CF clinical team. On average, people with CF spend 4 hours a day on treatment.

We asked CF health professionals what aspects of CF health PIP assessors typically fail to consider. This is what they said:



This significant daily treatment burden is frequently overlooked in assessments, contributing to a wider lack of understanding of the realities of living with CF. For example:

- Assessors often assume that people with CF who are in work do not have significant difficulties with daily living activities. This overlooks the reality that many people continue working despite substantial health challenges.
- Assessors frequently misunderstand or overlook the impact of joint pain and fatigue. In some cases, functional ability is inferred simply because someone is able to drive an unadapted car.
- Assessors also fail to recognise the issues around maintaining a healthy weight (people with CF often have to eat a specialist, high-calorie, nutritious diet to account for pancreatic insufficiency), living with comorbidities such as CF diabetes, and the impact of having a lifelong condition on their mental health.
- There is regularly no understanding of the preventative nature and burden of treatments, which are important to prevent exacerbations and infections and can take hours to complete every day.

This lack of understanding is reflected in assessment reports. People with CF are often shocked by conclusions that show little understanding of CF.

> “I feel that those involved in PIP and how it is assessed have no knowledge or understanding of CF and how it impacts an individual.” – CF nurse

> “The assessors appear to have very little understanding of experiences of living with a life-limiting condition.” – CF social worker

> “[He had a] face-to-face assessment. A totally degrading experience and he came out of the interview in a dreadful state… [The assessor] did not know anything about CF. The humiliation was unbelievable. He now refuses to reapply. He lives with us, we are both retired, so help him financially as best as we can. When we have passed, goodness only knows what will happen.” – parent of son with CF

A stark example of this lack of understanding is that a few respondents told us they or their patient were asked: “How long have you had CF?” As CF is a lifelong genetic condition, this shows a worryingly fundamental lack of understanding of the basics of CF.

The assessment criteria do not reflect the nature of CF. Combined with poor assessor knowledge, this means many questions are not relevant to CF. For example, some respondents told us they were asked if they could lift their arms above their heads, which is not usually relevant to CF.

- Only 10% of the CF community felt that all the questions the assessor asked were relevant to their daily life and mobility.
- Half of them (47%) felt that none of the questions were relevant.
- Only 1 in 10 (14%) CF health professionals said most of the questions were relevant to people with CF.

> “I felt I was being asked to jump through hoops that didn’t fit my condition – questions about whether I was able to open a jar, or assessments of the strength of my lower legs.” – person with CF

> “Many of the questions were irrelevant. When my son tried to go into detail or explain further he was stopped… They really wanted yes or no answers and if he answered no but tried to explain why, or that his condition can change, they were not interested.” – parent of son with CF

People who said their assessor did not ask relevant questions were twice as likely to receive no points for the mobility component of their PIP award compared with the average survey respondent.

Recommendation: Ensure all PIP assessors have a basic understanding of CF, including fatigue, infection risk, fluctuating health, and daily treatment burden. Develop and deliver mandatory training in partnership with Cystic Fibrosis Trust.

The fluctuating nature of CF is not taken into account

A key aspect of CF is that health can change in unpredictable ways. Symptoms can change rapidly, and many people with CF experience periods of severe, acute ill health that disrupt normal life, work, and education.

In 2024, people with CF spent an average of 14 days in hospital on IV antibiotics.[11] However, the PIP assessment does not reflect this reality.

Our research found:

- 2 in 3 (64%) members of the CF community felt their assessor did not understand and take into account the fact that their CF varies a lot
- 9 in 10 (95%) CF health professionals think assessors typically do not take fluctuating health into account during assessments.

> "The [PIP] system doesn't handle fluctuating conditions well. CF symptoms can vary day to day." – CF social worker

> "The assessor demonstrated a dangerous lack of knowledge of CF and appeared insufficiently trained in understanding hidden disabilities, particularly the fluctuating and invisible impact they have on daily life." – parent of child with CF

> "It seemed the assessors didn't understand fully just how vastly different my health can be, not only day to day but throughout the year. I have good days and they're very good but on days where my health is at a low – I cannot leave bed. I found it quite difficult to verbalise to the assessor a bad health day accurately without being misunderstood." – person with CF

Recommendation: Reform PIP rules, including the 50% rule, activity descriptors, and informal observations, so they properly reflect fluctuating conditions, fatigue, infection risk, and real-world barriers.

PIP's 50% rule does not work for people with CF

Under the "50% rule", if a condition affects someone's ability to carry out an activity for more than half of the year, it should be treated as affecting them all the time. In practice, we find this often depends on the assessor's judgement, and points are not often awarded on this basis.

The rule also fails to reflect the reality of fluctuating conditions. For example, if the ability of someone with CF to perform a daily task is affected for five months[12] of the year, they receive fewer or no points for this. This means someone could struggle with, or be unable to complete, an activity for a significant part of the year, but still receive a low score for this activity.

> "The PIP system does not take account of variability or allow for flexibility for variable conditions, particularly when asking about mobility (distance that can be walked) and whether activities of daily living can be carried out." – CF social worker

> "The questions are on an all or nothing basis – [the idea] you either can or can't do something. There doesn't seem to be any consideration for the in between."
> – person with CF

Recommendation: Revise the 50% rule to better reflect the reality of fluctuating conditions, such as fatigue, infection risk, and real-world barriers.

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[11] UK Cystic Fibrosis Registry 2024

[12] This is a simplified summary of the legal test that should be applied to fluctuating conditions. More information about the nuance of the legal test can be found here: https://pipinfo.net/issues/fluctuating-conditions

Informal observations lead to unfair assessments of people with CF

During assessments, PIP assessors can make 'informal observations'. These are judgements about a person's ability based on the way they look, sound, or behave. For people with CF, this can lead to unfair decisions.

> "Just because you look them in the eye, [it] doesn't warrant being told your medication for extreme anxiety isn't relevant. Yes, that is what he was told."
> – parent of son with CF

> "[I] feel like the assessors don't believe me when I talk about my condition as I don't look unwell." – person with CF

Because CF fluctuates day to day, informal observations can lead to unfair assumptions and prevent people from receiving the support they need.

For example, if someone with CF does not sound breathless on the day of their assessment, this may be used to suggest their lungs are not severely affected. In reality, someone with CF can have significantly poor lung function without sounding breathless.

CF is also a multi-organ condition, not just a lung condition. It can cause a range of comorbidities that affect someone's daily life. For example:

- one-third of adults with CF have CF diabetes
- one-quarter have liver disease.

Assessors may also assume that someone who does not appear underweight does not need support with nutrition. In reality, people with CF often require dietary support and supplements to maintain weight and can rapidly lose weight during an infection.

> "The DWP assume someone is on a modulator and their lung function is much improved without considering the whole system impact of CF." – CF consultant

> "I use the gym to do what I can to keep my CF controlled, but I'm a big guy. So I don't look unwell at all. Even though going to the appointment was difficult for me I could tell the person conducting the interview just looked at me and made up their mind instantly… I was told a letter would come out to me and I lost. I felt so disheartened, like I was told I was lying about my illness." – person with CF

> "[They] basically called my daughter a liar. Just because she stood up, she was told there was nothing wrong with her and she could run a marathon!"
> – parent of daughter with CF

Some people with CF who were in work felt this affected how they were assessed.

> "I felt that because I was working I wasn't taken seriously." – person with CF

Informal observations are given too much weight by assessors

Informal observations are supposed to be balanced with evidence from medical professionals. However, we believe this is often not happening in practice.

Assessments provide a snapshot of someone on a single day. In contrast, medical evidence provided by health professionals shows how a person's condition affects them over time. As outlined above, informal observations are particularly unreliable for people with CF due to the fluctuating nature of the condition.

Despite this, informal observations are sometimes used to contradict medical evidence showing someone cannot perform a task. More than 1 in 3 (35%) CF health professionals said they believed PIP assessors "almost totally" or "significantly" rely on informal observations to decide whether to recommend awarding PIP.

> "Assessors focus on informal observations, such as how a person walks into a room, and use this to contradict medical evidence and the claimant's own testimony." – Fiona Dowdall, Co-chair of UK Psychosocial Professionals in CF Group (UKPPCF)

> "I have read assessor comments about their [the PIP assessor's] observations of the patient's breathing during the assessment, which is clearly not a relevant or useful measure." – CF social worker

CF is an invisible condition. When someone appears well, this can lead assessors to dismiss both medical evidence and the person's own account of their condition.

Recommendation: Do not use informal observations when assessing people with fluctuating conditions such as cystic fibrosis, as they rarely provide an accurate reflection of daily functioning.

PIP activity criteria: background to how PIP is assessed

PIP is split into two components: the daily living component, which is based on your ability to perform daily living tasks, and the mobility component, which is based on your ability to get around and plan and follow journeys. Whether you are awarded each component is based on 12 activities: 10 related to daily living and 2 related to mobility.

The ten activities for daily living are:

1. preparing food
2. taking nutrition
3. managing therapy or monitoring a health condition
4. washing and bathing
5. managing toilet needs or incontinence
6. dressing and undressing
7. communicating verbally
8. reading and understanding signs, symbols and words
9. engaging with other people face to face
10. making budgeting decisions.

The two activities for mobility are:

1. planning and following journeys
2. moving around.

Each activity has a series of descriptors which are worth a number of points. Assessors ask questions to decide which descriptors the claimant meets on the majority of days within each activity and, therefore, how many points they receive. Where more than one descriptor applies, only the descriptor with the highest point value is awarded, provided it applies on the majority of days.

There is no requirement for assessors to have specialist knowledge in relation to an applicant's condition or functional limitations.

The PIP assessment criteria do not capture the reality of living with CF

Our survey of CF health professionals found that fewer than 1 in 10 (8%) believe all 12 activity areas for PIP accurately capture how CF affects daily life and mobility.

We received an enormous number of responses from the CF community and health professionals stating that the criteria do not reflect the burden of treatment people with CF have to perform daily:

> "By its very premise, it systematically fails to recognise the extent of self-care needed by the sufferer to remain in "good health" and thus minimise clinical interventions." – parent of daughter with CF

> "It would be much better for the questions and the PIP criteria to be reflective of living with CF on day-to-day basis and treatment burden rather than the activities of daily living." – CF nurse

> "[There needs to be] more consideration to burdensome, daily treatment and medications rather than the current main focus on functional tasks."
> – CF social worker

Recommendation: Reform activity descriptors to more accurately reflect life with CF.

Below, we highlight specific examples of how the current assessment criteria, descriptors, and points do not work for people with CF and require reform.

Activity 1: Cooking

Recommendation: Criteria should reflect the additional calorific and nutritional requirements associated with conditions such as cystic fibrosis.

Explanation: Many people with CF require a specialist diet to stay well. The criteria don't allow a 'special diet' to be in scope, meaning the extra calories someone with CF needs to stay well are not considered.

Activity 2: Taking nutrition

Recommendation: Criteria should recognise conditions that require strict nutritional timing, including where food intake must be coordinated with medication.

Explanation: Many people with CF, particularly young people, need support to manage medication and nutrition timing. The existing criteria don't account for the need for enzyme supplements to enable digestion and absorption, or timing food intake with medications such as Kaftrio.

Activity 3: Treatments

Recommendation: Criteria should recognise the combined burden of medication, monitoring, and therapies, rather than treating them separately.

Recommendation: Criteria should award points for managing complex or time-consuming treatments on their own, acknowledging the heavy burden this places on them even without help from others.

Explanation: Many people with CF have extensive daily treatment regimens, including medication, therapies, and monitoring of stools, sputum, and blood sugars. Because the criteria consider "medications, managing and monitoring" (3B of criteria) and "therapies" (3C-F) separately, this means the entire burden for people with CF is not recognised.

People only score in these criteria where help is required. This means someone spending several hours a day on treatment receives no recognition if they manage independently. This approach does not reflect the reality of living with CF or encourage independence.

Activity 5: Toilet needs

Recommendation: Criteria should recognise additional toilet needs, including incontinence, leaking, or the need to remain close to toilet facilities.

Explanation: Most people with CF experience bowel or stomach issues. As a result, they may need to stay near a toilet or respond urgently. This is a very debilitating symptom which affects daily life, can cause social embarrassment, and limits employment prospects. Despite this, unless you need an aid or assistance on most days, this doesn't score any points.

Activity 9: Social interaction

Recommendation: Criteria should recognise conditions that affect social interactions because they are deemed unsafe, including where infection risk makes interaction with people harmful.

Explanation: Cross-infection, or cross-contamination, occurs when one person spreads an infection to another, either directly or indirectly. For people with CF, cross-infection poses a particular threat, meaning people with CF should not meet face to face. Many people with CF report issues with mixing with others in a normal way and are at increased risk of becoming very unwell if they catch an infection, sometimes requiring hospital admissions and time off work. Because of this risk of infection for people with CF, and because of anxiety caused by this, this can prevent them mixing in a way that they would like to. Currently, these criteria only consider a person's ability to engage with other people in a contextually and socially appropriate manner. It does not take into account a person's ability to engage with other people because of infection risk.

Activity 11: Going out

Recommendation: Criteria should be reordered so that individuals who cannot leave the house at all due to mental health conditions receive the highest score.

Explanation: As outlined above, people with CF are often unable to go out because of anxiety about infection risk. Under current criteria, someone who cannot go out at all due to mental ill health scores 10 points (under 11E), while a person who can go out accompanied scores 12 points. This does not reflect the level of restriction experienced and is not a fair way of awarding points.

Activity 12: Mobilising/walking

Recommendation: Criteria should reflect real-world mobility challenges by including stairs and inclines.

Explanation: Many people with CF experience breathlessness when walking on slight inclines or climbing stairs. The current criteria only consider difficulties with mobility and walking on level ground, which is not reflective of the environments people encounter in daily life. As a result, many people with CF do not score in this activity despite experiencing difficulties.

The way people with CF are assessed has a big impact

After submitting a PIP claim form, a minority of claimants receive a decision based on the form and supporting evidence. However, most are asked to attend an assessment. This could be face to face, by video call, or over the telephone.

Across all conditions, people who have face-to-face assessments have a lower success rate than those who are assessed remotely. Over the last few years, this gap has been growing. In 2024, claimants who had a face-to-face assessment were almost 25% less likely to get an award than claimants who had a telephone or video assessment. This is a particular concern for people with CF as they are disadvantaged by face-to-face informal observations which fail to take into account the fluctuating nature of their condition. In addition, people with CF are more vulnerable to illness than the general population and therefore often try to avoid unnecessary contact with others to reduce the risk of picking up an infection. This means they can be reluctant to travel for a face-to-face assessment.

In the Pathways to Work Green Paper, the Government committed to increasing the percentage of PIP assessments conducted face-to face to 30%. As noted above, this leads to a higher proportion of applications being rejected. While people can specify whether they would prefer a face-to-face or remote assessment, this is not guaranteed. We are concerned that this target will lead the DWP to pressure people with CF, who may have mobility issues or increased infection risk, to have assessments face-to-face when remote options are available.

Recommendation: Reduce the gap in award rates between face-to-face and remote PIP assessments.

Recommendation: Give people with cystic fibrosis a genuine choice between face-to-face or remote assessments.

Disability Living Allowance and PIP

DLA and PIP background

Disability Living Allowance (DLA) and Personal Independence Payment (PIP) are both non-means-tested, non-taxable cash benefits designed to help with the extra costs of disability.

People who receive them get between £121.20 and £778.40 every four weeks, depending on how their needs are assessed. DLA is for children up to the age of 16 and PIP is for anyone aged over 16.

If you receive DLA, you will be invited to make a claim for PIP soon after you turn 16. You continue to receive DLA payments while you wait for your PIP decision to be made. If your PIP claim is accepted, you will move from PIP to DLA. If your PIP claim is rejected, you will not receive PIP and you will also stop receiving DLA.

Both DLA and PIP are intended to help with the costs of disability. However, although we know the extra costs people with CF face are unlikely to change when they turn 16, the criteria for DLA and PIP are different, and people can receive very different outcomes.

> "Unlike DLA, PIP does not award for how a young person's day differs to that of someone without CF, including the care and support they need."
> – CF social worker

Going from something to nothing

Three quarters (74%) of people with CF aged 0-15 receive DLA. In contrast, less than half (46%) of people with CF aged 16 and above receive PIP.[13] This is a big drop off considering their condition is very unlikely to have changed significantly during this time.

> "Lots of children that change to PIP from DLA have been declined after being on DLA successfully for all their lives." – CF nurse

Our research found:

- 8 in 10 (85%) people with CF who have applied for, but never received, PIP did previously receive DLA
- 9 in 10 (90%) of this group described their health as worse now than when they were receiving DLA.

If someone's health is worse now than when they qualified for DLA, it doesn't make sense that they don't qualify for PIP. Many adults with CF and parents of children with CF told us how unfair they found this.

> "She answered all questions honestly and was rewarded zero points after receiving the higher rate of DLA for 14 years." – parent of daughter with CF

> "We answered all the questions in the same way as we had previously answered for DLA, yet we felt completely disregarded." – parent of child with CF

> "Overall, how can I go from having DLA for 16 years, which supported me and my care, to having nothing all by just changing the name from DLA to PIP? I need the support and care more than ever now at my age." – adult with CF

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[13] Based on Cystic Fibrosis Trust Registry data (2024 Annual Data Report, amended November 2025), there are 3,688 people with cystic fibrosis in the UK aged 0-15, of which 2,729 receive DLA according to Department for Work and Pensions Stat-Xplore data (August 2025).

When a child loses DLA, it can also trigger the loss of linked benefits that a parent might receive, like Carer's Allowance. Roughly a third of parents of children with CF receive Carer's Allowance.[14]

Recommendation: Ensure an equitable approach to awarding DLA and PIP so that young people who receive DLA do not face a sudden loss of support after age 16.

Increasing the minimum age to claim PIP from age 16 to 18

The Government is considering raising the age at which people move from claiming DLA to PIP from 16 to 18. In principle, Cystic Fibrosis Trust welcomes this change because it would allow more people with CF to provide stronger medical evidence with their PIP application. In the Government's Pathways to Work Consultation, people were asked what age young people should start claiming PIP. The most common response was 18.[15]

Reducing the burden on young people

Raising the minimum PIP age to 18 would make it easier for young people to manage claims. The PIP process, which we know is long and complicated for everyone, can be particularly challenging for younger people.

For example, unlike DLA, if you are declined PIP and then appeal, you are expected to attend the PIP tribunal hearing. This is emotionally tough for anyone and an unreasonable burden to place on a 16 or 17 year old.

Some of the PIP criteria is also less relevant to 16 and 17 years olds who are more likely to be living at home and therefore doing little cooking (Activity 1) and budgeting (Activity 10) themselves. This makes it difficult for assessors to know how to award points.

> "Almost every DLA to PIP claim case is led by the parents, who say - how is a 16-year-old supposed to be able to undertake the application?" – CF social worker

Getting accurate medical evidence

People with CF are cared for by either a paediatric CF centre or adult CF centre. Each centre is made up of a multidisciplinary team (MDT) of CF consultants, dietitians, social workers,[16] psychologists, and nurses. These teams have specialist knowledge of CF and an in-depth understanding of their patients' health, so can usually provide strong supporting medical evidence for benefit applications.

Most people with CF transition from paediatric to adult care at around age 16, but it can happen at any point between 14 and 18 based upon individual needs.

At the moment, many people with CF are applying for PIP for the first time aged 16, having only recently transferred to adult CF care. This means their new MDT often doesn't know them well enough yet to explain how CF affects their life.

Because good medical evidence is key to whether someone with CF is awarded PIP, this puts them at a disadvantage in their application. People with CF can ask their old paediatric centre to provide supporting medical evidence, but as this falls outside of the centre's role, it isn't always possible.

> "The timing is all wrong as well. It should be later, as they are transitioning to adult care and the doctors don't know enough about them to give good evidence."
> – parent of child with CF

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[14] The Cost of Cystic Fibrosis

[15] Government Response to the Pathways to Work Consultation - GOV.UK

[16] CF centres in Scotland do not have social workers.

Raising the minimum PIP age to 18, as the Government is considering, would help address this. By 18, most people with CF would have been cared for by their adult CF centre for a long enough period before applying for PIP that the MDT would be able to provide accurate supporting medical evidence.

DLA awards must also be extended

This change will only work if DLA awards are also extended up to age 18.

At the moment, children are usually reviewed for DLA around age 14, with awards lasting until they can apply for PIP at age 16. If the minimum PIP age rises to 18, the DLA awards must also last until 18. Otherwise, some 16-, and 17-year-olds with CF would need to reapply for DLA shortly after moving to adult CF care, and would therefore encounter the same problem of relying on a new MDT that doesn't yet know them well enough to provide accurate supporting medical evidence.

To prevent young people falling through the gap, the Government should increase the DLA award length to age 18, in line with the higher minimum age for PIP.

If the Government does not raise the minimum age for PIP to 18, or does not extend DLA awards to 18, it should instead follow Scotland's approach, where people can choose to switch to the adult equivalent benefit at any point between 16 and 18.

This flexibility would allow people with CF to switch from DLA to PIP at a time that aligns with their transition from paediatric to adult CF care, helping ensure they can get medical evidence from an MDT that knows them well.

Recommendation: Increase the minimum PIP age to 18 and extend DLA awards given at reviews around the age of 14 to last until age 18.

Alternative recommendation: Follow Scotland's approach and allow people to choose when to switch from DLA to PIP at any point between 16 and 18.

Closing remarks

My thoughts after 10 years supporting people with CF to access PIP

Since 2016, Cystic Fibrosis Trust's Welfare and Rights Advisor, Sangeeta Enright, has supported around 2,000 people with CF with PIP claims, reviews, and appeals. Here, she sets out her experience of the PIP process, drawing on evidence collected through a decade of frontline work.

"PIP is often discussed through the lens of outcomes; whether someone receives an award or not. But for many of the people I help, the journey itself is the most difficult part. Applying for PIP is longwinded, cumbersome, inconsistent, and is deeply upsetting for most of my clients with CF and their families. Many find the process unwieldy and unclear, are overwhelmed with the task, and require specialist help to get through it.

Most of my clients initially trust the system. But over the course of the process, they lose confidence in it. As a result, they approach reassessments with significant anxiety. They fear having to repeatedly justify the impact of their condition and worry that they may lose the support they rely on to manage their health.

Between July 2024 and February 2026, I assisted in 90 PIP outcomes. Of these:

- only 10 people received 10-year (or ongoing) awards
- 3 years was the most common length of award
- 39 had to go to appeal, of which one-third had their decision overturned by DWP prior to the appeal hearing. The rest were all overturned by the Tribunal.

That so many people with CF have their decision overturned shows how many are receiving the wrong decision. You should not have to appeal to get the right decision.

As this report shows, people with CF face challenges at every stage of the PIP process. As a result, many cases are only resolved at appeal. Successful appeals often rely on the correct application of case law, particularly the legal test of whether an activity can be completed "reliably", alongside credible oral evidence from the claimant or their carer.

Even then, I frequently see DWP appeal responses that place disproportionate weight on the assessor's report, even where strong contradictory evidence has been submitted. It is rare for the DWP to revise its position at this stage. Instead, cases proceed to tribunal, where panels properly weigh all available evidence, including the credibility of oral testimony. Tribunals also apply the reliability criteria correctly from the outset and ask probing questions to understand the full impact of the condition on a person's daily life.

It should not be so difficult, and require so many stages, for someone with CF to be awarded the PIP they are entitled to.

I would like to see a PIP system that genuinely supports the independence and choices of people with CF. Too many people with CF, who already live with the knowledge of a shortened life expectancy, are forced to spend their precious time battling the system.

A good system would have clearer and more transparent claim and review processes, alongside a fairer approach to gathering evidence. Medical evidence from specialists who understand the condition should carry greater weight than assessments conducted by external health professionals with limited knowledge of CF.

The current system is no longer trusted by many people with CF and, in some cases, it actively causes harm and stress. PIP entitlement should be decided correctly and quickly, payments should be made promptly, and the system should be underpinned by a genuine commitment to helping people with CF live well and independently."

Our asks in full

The PIP system

- Design a new PIP system that better supports people with lifelong conditions, while ensuring reforms do not make it harder for people with CF to qualify.
- Increase PIP rates annually by more than the previous September's Consumer Price Index (CPI), reflecting the higher cost of living faced by disabled households due to increased spending on essentials such as food and energy.
- Instil a culture of trust in the PIP system to reduce the adversarial nature of the process.
- Reduce PIP decision times to reduce the huge impact on mental and physical health and ensure people get their PIP payments faster.

PIP claim and review forms

- Work with patient charities and social workers to redesign PIP claim and review forms so they are clearer, shorter, less repetitive, and more relevant to people with long-term conditions such as CF.
- Remind claimants clearly throughout PIP forms that, if their condition fluctuates, they should describe how they experience most days and how this affects their ability to complete tasks.
- Encourage claimants to submit medical evidence on PIP forms. Where claimants do not provide evidence, proactively seek evidence from named health professionals and contact claimants if further information is required.
- Include signposting on PIP claim and review forms to organisations that can help them complete the form.
- Explain clearly on PIP forms that claimants can submit supporting evidence and outline the types of evidence that can be provided.
- Provide templates to help claimants collect supporting evidence from health professionals, carers, or family members.
- Make clear on PIP claim forms that supporting evidence can be submitted after the claim form, clearly state the deadline for submitting additional evidence, and allow deadlines to be extended when needed.
- Include the descriptors used to assess eligibility on PIP claim and review forms so claimants understand what decision-makers can and cannot take into account.
- Offer claimants the option to start a PIP claim online.
- Allow claimants to choose whether to receive their PIP claim form online or by post.

Assessments

- Give greater weight to medical evidence from specialist teams, such as CF multidisciplinary teams (MDTs), than to evidence gathered during assessments.
- Provide PIP assessment reports automatically to claimants following their assessment so they can identify inaccuracies and challenge decisions where necessary.
- Ensure all PIP assessors have a basic understanding of CF, including fatigue, infection risk, fluctuating health, and daily treatment burden. Develop and deliver mandatory training in partnership with Cystic Fibrosis Trust.
- Do not use informal observations when assessing people with fluctuating conditions such as cystic fibrosis, as they rarely provide an accurate reflection of daily functioning.
- Revise the 50% rule to better reflect the reality of fluctuating conditions, such as fatigue, infection risk, and real-world barriers.
- Award longer PIP awards to people with lifelong conditions such as CF to prevent repeated, stressful reassessments.
- Give people with cystic fibrosis a genuine choice between face-to-face or remote assessments.
- Reduce the gap in award rates between face-to-face and remote PIP assessments.
- Record PIP assessments by default unless the claimant chooses to opt out.
- Pay claimants a reduced rate of PIP while they wait for their appeal, and do not require repayment if the appeal is unsuccessful.
- Ensure the PIP process is open, transparent, and built on trust so that people who are wrongly denied, or given an inadequate award, feel able to appeal.

Criteria

- Reform activity descriptors to more accurately reflect life with CF. Specifically:
  - Activity 1 criteria should reflect the additional calorific and nutritional requirements associated with conditions such as cystic fibrosis.
  - Activity 2 criteria should recognise conditions that require strict nutritional timing, including where food intake must coincide with medication, such as taking Pancreatic Enzyme Replacement Therapy (PERT) to ensure nutrition is absorbed.
  - Activity 3 criteria should recognise the cumulative burden of treatments, rather than any one medication or therapy needing to score highly to be awarded points.
  - Activity 3 should give points to claimants who manage complex or time-consuming treatments on their own, acknowledging the heavy burden this places on them even without help from others.
  - Activity 5 criteria should recognise additional toilet needs, including incontinence, leaking, or the need to remain close to toilet facilities.
  - Activity 9 criteria should recognise conditions that affect social interactions because they are deemed unsafe, including where infection risk makes interaction with strangers harmful.
  - Activity 11 criteria should be reordered so that individuals who cannot leave the house at all due to mental health conditions receive the highest score.
  - Activity 12 criteria should reflect real-world mobility challenges by including stairs and inclines.

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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