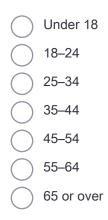




## **Welfare Reform Survey**

Please take my survey - thanks!

1 How old are you (or the person you care for)?\*



2 Do you (or the person you care for) have a diagnosis of ME/CFS or Long Covid?\*

Yes - I have a diagnosis of ME/CFS
 Yes - I have a diagnosis of Long Covid
 No - But I experience all of the key symptoms
 No

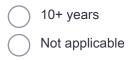
\* Choose one.

**3** How long have you (or the person you care for) had the diagnosis of ME/CFS or Long Covid?\*

) Less than a year

) 1-5 years

) 6-10 years



**4** How would you describe the severity of your (or the person you care for) ME/CFS or Long Covid at the present time?\*

Mild (able to work/volunteer part-time with activity and mobility limitations)

) Moderate (mostly housebound, limited activity and mobility)

Severe (housebound/bedbound, minimal daily activity and mobility)

Very severe (completely bedbound, needing full-time care)

\* Choose one.

**5** Which of the following benefits do you (or the person you care for) currently receive? (tick all that apply)

٦	Personal Independence Payment (	PIP)	
		/	

Employment and Support Allowance (ESA)

Universal Credit (UC)

Attendance Allowance

Disability Living Allowance (DLA)

Carers Allowance

I don't receive any benefits



Other (please specify)

\* Choose all that apply.

6 Have you (or the person you care for) ever applied for Personal Independence Payment (PIP)?\*

- Yes, and I currently receive it (I remain eligible)
- Yes, but I no longer receive it (I am not eligible)
- Yes, but it was withdrawn unfairly upon review (I still think I am eligible)
- Yes, but PIP was refused (I didn't challenge the decision)
- Yes, but PIP was refused (despite challenging the decision)
- Yes, but I withdrew my application
- No, I've not applied because I didn't think I was eligible
- No, I've not applied because I didn't know it was available
- Prefer not to say

\* Choose one.

**7** If you (or the person you care for) have never applied for PIP, please tell us why (select all that apply):\*

I didn't think I would qualify

I thought the process would be too difficult

I was put off by how others with ME/CFS or Long Covid were treated
I was too unwell to attempt it, and no help was available
I found the application form overwhelming
I was worried about obtaining medical evidence
I was worried about the medical assessment
I had a bad experience in the past with another benefit application
I didn't know how to get help with the application
I didn't know PIP was available to me
I had not heard about PIP before
Not applicable
Other (please specify)

\* Choose all that apply.

8 Have you (or the person you care for) ever felt anxious, intimidated or distressed about applying for PIP or another benefit?\*

Yes — very much so Yes — somewhat No — not really No — not at all Prefer not to say

\* Choose one.

**9** If you (or the person you care for) were put off from applying for PIP, what were the main reasons? (Select all that apply)\*

I was too ill
I wouldn't be believed
I would be judged unfairly
I would be intimidated
I had been treated unfairly in the past
I wasn't able to complete the application on my own
I had nobody to help me through the process
They wouldn't understand ME/CFS or Long Covid
The impact of my illness would be dismissed
The application form
The face-to-face medical assessment
The impact of the process on my health
The thought of having to approach my GP for medical evidence
The process itself and the collation of evidence
Other (please specify)

\* Choose all that apply.

**10** Have you (or the person you care for) delayed applying for PIP because you were too unwell?\*

- Yes I waited months before applying
  - Yes I waited years before applying

Yes - I still haven't applied

No - My health status didn't delay the application (I was able to do it myself)

) No - My health status didn't delay the application (I had help and it was done on my behalf)

No - I do not intend applying

\* Choose one.

**11** In your opinion, how well does the current PIP system work for people with ME/CFS and Long Covid?\*

- Very well
  Reasonably well
  Not very well
- Not at all
- I don't have an opinion
- \* Choose one.

**12** What changes to the current PIP system would you (or the person you care for) like to see that would make it fairer?

You might consider changes in general or changes that could make it fairer for people with long-term fluctuating conditions.

**13** Please share anything else you (or the person you care for) would like policymakers to understand about why people with ME/CFS or Long Covid may avoid or delay applying for welfare benefits.

14 If you (or the person you care for) receive PIP, are you in paid employment?

Full-time = usually 35+ hours a week.
Part-time = less than 35 hours a week.

**Hybrid** = working from home some days and on other days at a place of business which usually implies a commute is necessary.\*

- Yes full-time
  - ) Yes full-time at home
  - Yes full-time hybrid
- Yes part-time
- Yes part-time at home
- Yes part-time hybrid
- Yes self-employed
- Yes self-employed at home
- Yes self-employed hybrid
- No I am currently seeking work
- ) No I am not able to work due to my health
- Prefer not to say
- ) I do not receive PIP

\* Choose one.

**15** If you (or the person you care for) currently receive PIP, has it enabled you to remain in work or return to work?\*

- Yes PIP helped me to remain in work
- Yes PIP helped me return to work
- ) No Even with PIP, my health prevents me from working

\* Choose one.

**16** In what ways has receiving PIP helped you (or the person you care for) remain in work or return to work? (Select all that apply)\*

It means I can afford to work less hours and better manage my health. It reduces financial stress, making the work I could do more enjoyable.

It allows me to pay for extra care and support that enable me to work.

It covers transport or mobility-related costs.

It funds home adaptations or assistive technology.

Not applicable

Other (please specify)

\* Choose all that apply.

**17** If you (or the person you care for) were to lose your PIP award, how would it impact your ability to work?\*

- I would be unable to continue working
- I would have to reduce my hours or the amount of work I can do
- I would struggle financially but would try to continue working
- ) It would not affect my ability to work
- ) Other Please explain:

\* Choose one.

**18** If losing PIP would negatively impact your (or the person you care for) ability to work, please explain how.\*

**19** Have you (or the person you care for) ever had to give up work, reduce hours, or turn down opportunities because you were refused PIP or had your award reduced?\*

- Yes I had to stop working altogether
- Yes I had to reduce my working hours
- Yes I turned down a job or promotion
- Not applicable

\* Choose one.

**20** What additional support — financial or otherwise — would help you (or the person you care for) stay in work or return to work?\*

21 What components of PIP do you (or the person you care for) currently receive?\*

Daily Living and Mobility

) Daily Living only

) Mobility only

\* Choose one.

**22 PIP: Daily Living Component:** Did you (or the person you care for) receive a Daily Living component as part of your current PIP award?\*

YesNoDon't know

**23** How many points were you (or the person you care for) awarded for each of the following Daily Living activities? (Please enter the number of points you received for each)\*

a) Preparing food

b) Eating and drinking

c) Managing treatment or medication

d) Washing and bathing

e) Managing toilet needs or incontinence

f) Dressing and undressing

g) Communicating verbally

h) Reading and understanding written information

i) Mixing with other people

j) Making budgeting decisions

24 How many points were you (or the person you care for) awarded for each of the following Daily Living activities? (Please enter the number of points you received for each)\*

a) Preparing food

b) Eating and drinking

c) Managing treatment or medication

d) Washing and bathing

e) Managing toilet needs or incontinence

f) Dressing and undressing

g) Communicating verbally

h) Reading and understanding written information

i) Mixing with other people

j) Making budgeting decisions

**25** Did you (or the person you care for) receive a Mobility component as part of your current PIP award?\*



**26** How many points were you (or the person you care for) awarded for each of the following Mobility activities?\*

a) Planning and following a journey

b) Moving around

**27** Have you (or the person you care for) ever received the enhanced Daily Living component of PIP while scoring fewer than 4 points in any single Daily Living activity? (Please answer based on your official decision letter or assessment outcome.)\*

- Yes I received the enhanced award but did not score 4 or more points in any one activity
- No I scored 4 or more points in at least one Daily Living activity
- I don't know / I can't remember my scores per activity
- Not applicable I did not receive the Daily Living component of PIP

**28** Do you (or the person you care for) expect to lose your PIP Daily Living award as a result of the proposed reforms because you did not score 4 or more points in any Daily Living descriptor?

(This relates to concerns about proposed changes to eligibility criteria.)\*

- Yes I'm concerned I may lose my award for this reason
  - No I scored 4 or more points in at least one Daily Living activity
  - ) No I do not expect to lose my award for this reason
  - I'm not sure what my scores were per activity
  - Not applicable I do not receive the Daily Living component of PIP

\* Choose one.

**29** Appeals and Reconsiderations Did you (or the person you care for) need to challenge the initial PIP decision?\*

- No, I accepted the decision
- Yes, I requested a Mandatory Reconsideration
- Yes, I appealed the decision to a tribunal
- Other (please specify)

**30** If you (or the person you care for) challenged the PIP decision, did it result in a change to your award?\*

Yes, I received a higher award

No, my award stayed the same

) No, the challenge was unsuccessful

Not applicable

\* Choose one.

**31** Please describe briefly why you decided to appeal or seek a reconsideration. If you decided not to appeal, please describe why.

32 If known, what was the total number of points before and after the appeal?

Before: Daily Living

Before: Mobility

After: Daily Living

After: Mobility

**33** Please describe any difficulties you experienced during the application or assessment process (e.g., attending in-person assessments, problems with home-assessments, understanding and completing forms, expressing the extent to which you are disabled, obtaining evidence such as medical reports, being believed, etc.):

34 How did the assessment process affect your (or the person you care for) health and wellbeing?\*

- No impact
- ) Mild negative impact
- Moderate negative impact
- Severe negative impact
- Please explain (optional):

\* Choose one.

**35** Did you (or the person you care for) receive help from a professional benefits advisor (e.g., Citizens Advice) when applying for or appealing a benefit (e.g. PIP, ESA, UC)?\*

- Yes, for my initial application
- Yes, for a reconsideration or appeal
- ) Yes, for both application and appeal
- ) No, I did it alone
- No, I had help from a friend/family member

No, I wanted help but couldn't access it

Not applicable

\* Choose one.

**36** If you did receive help from a benefits advisor, where was this support based? (Select all that apply)\*

Citizens Advice
Local council or social services
ME/CFS or Long Covid charity
Other charity
Legal aid / welfare rights service
GP surgery or health professional referral
Independent advisor (paid)
I cannot remember
Other (please specify)

\* Choose all that apply.

**37** How easy was it to access a benefits advisor when you (or the person you care for) needed one?\*

Very easy — I got help quickly and without issue

- Fairly easy some delays or minor difficulties
- ) Difficult I faced barriers or long delays
- ) Very difficult I could not get help at all
- ) Not applicable

**38** If you (or the person you care for) had to wait for an appointment, how long did you have to wait before receiving help from a benefits advisor?\*

Less than 1 week
1–2 weeks
2–4 weeks
More than 4 weeks
I never received an appointment
Not applicable

\* Choose one.

39 How helpful was the advice or support you received from the benefits advisor?\*

- Extremely helpful made a major difference
- ) Helpful supported me with forms or understanding
- ) Somewhat helpful but limited in what they could do
- ) Not helpful didn't improve my situation

 $\bigcirc$ 

Not applicable / didn't receive help

\* Choose one.

40 In what ways did the benefits advisor help you? (Select all that apply)\*

Completing application forms
Writing supporting evidence
Understanding eligibility criteria
Preparing for a medical assessment
Requesting a Mandatory Reconsideration
Supporting an appeal
Providing moral/emotional support
Not applicable
Other (please specify)

\* Choose all that apply.

41 Please describe any barriers you faced in getting professional benefits advice

**42** In your view, how important is it to have access to free and professional benefits advice for people with ME/CFS or Long Covid?\*

Essential
 Very important
 Somewhat important
 Not important
 Don't know

\* Choose one.

**43** How do you (or the person you care for) feel about the proposed welfare reforms (e.g. changes to PIP criteria, increased conditionality )?

**44** What would you (or the person you care for) most like policymakers to understand about living with ME/CFS or Long Covid and the welfare system?

## **45 Important: Consent**

Do you consent to your anonymised responses being used in the MEA's submissions to the government, parliamentary committees, and MPs, and for a report to be published on the MEA's website and social media channels?\*



**46** What is the name of your MP?

**Please note:** We will only use this information to provide briefings to your MP, if we have received your consent to do so.\*

## 47 Important: Follow-Up

Would you be willing to provide a more detailed account of your experiences with PIP that we can use as an anonymous case study?\*

Yes

\* Choose one.





Thanks for taking this survey!