



Welfare Reform Survey

Please take my survey - thanks!

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

- ☐ Under 18
- ☐ 18–24
- ☐ 25–34
- ☐ 35–44
- ☐ 45–54
- ☐ 55–64
- ☐ 65 or over

* Choose one.

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

- ☐ 10+ years
- ☐ Not applicable

* Choose one.

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)

- ☐ 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- ☐ Yes, but it was withdrawn unfairly upon review (I still think I am eligible)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?*

- ☐ Yes
- ☐ No
- ☐ Don't know

* Choose one.

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?*

- ☐ Yes
- ☐ No
- ☐ Don't know

* Choose one.

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

* Choose one.

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)
-

* Choose one.

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

* Choose one.

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

☐ 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?*

- ☐ Yes
- ☐ No

* Choose one.

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
- ☐ No

* Choose one.



Thanks for taking this survey!