The replacement of Disability Living Allowance with Personal Independence Payment (PIP) for adults of working age is underway.

So we are sending out this questionnaire, asking about your experiences of claiming PIP.

If you reached your 65th birthday before the 9th of April 2013, you cannot claim PIP.

If you were born on or after the 9th of April 1948, please try to complete and return this questionnaire, even if your experience regarding PIP is already known to the 25% ME Group.

We have tried to make it simple and straightforward to complete.

- If you find there isn’t enough space for what you would like to say, please feel free to continue any of your responses on a separate sheet and return with the questionnaire.
- If you don’t know the answer to any of the questions, please just write in ‘don’t know’.
- If we ask ‘how long?’ something took and you’re not sure or it’s hard to think – you may prefer to give approximate dates instead – that’s fine

Because we are hoping to update this survey in future, we are asking you to let us know who you are. This will allow us to link up the experience you tell us about here with any feedback you give us about PIP at a later stage. We will do this by adding your membership number to the questionnaire(s), as unique identifier.

This front sheet with your name and address will be detached and stored securely.

For purposes of data analysis and reporting your replies will be anonymous.

Name: …………………………………………………………………………………………………………………………………………………………………………………………….
Address: …………………………………………………………………………………………………………………………………………………………………………………………….

We appreciate that a person with severe ME may need someone to help answer the questions, or to complete all of the questionnaire for them.

If you are responding on behalf of a 25% ME Group member, please use the space above to enter the name and address of the member that you are answering about.

__________________________________________________________

IF YOU REQUIRE THIS QUESTIONNAIRE IN LARGE PRINT, PLEASE CONTACT THE OFFICE ON 01292 318611
OR SEND AN E-MAIL TO: enquiry@25megroup.org

Thank You
25% M.E. Group Members’ Feedback on Personal Independence Payment (PIP)

Are you completing this questionnaire on behalf of the person with severe ME? yes / no (please circle)

If so - what is your relationship to the person that this questionnaire is about? .......................................................... - please answer the questions as though you were the person with severe M.E.

Q1. PLEASE TICK THE BOX THAT DESCRIBES YOUR SITUATION...

☐ 1. I have not claimed Disability Living Allowance (DLA) or Personal Independence Payment (PIP)
   you may tell us more about your decision not to claim in the space below; there are no further questions

☐ 2. I have been refused Disability Living Allowance and have not applied for PIP
   you may tell us more about this in the space below; there are no further questions

☐ 3. I am on Disability Living Allowance; I have not been notified about PIP yet
   please complete Q2 only (about DLA)

☐ 4. I was on DLA; I have been ‘invited’ / ‘selected’ to claim PIP but did not claim
   please use the space below to tell us why; and complete Q2 (about DLA); there are no further questions

☐ 5. I have claimed PIP; prior to this I was not on Disability Living Allowance
   please skip Q2 and respond to the rest of the questions

☐ 6. I am/was on DLA; I have been ‘invited’ or ‘selected’ to claim PIP and claimed
   please complete the rest of this questionnaire

☐ 7. I am/was on DLA; I have claimed PIP following a change of circumstances
   please respond to the query below, and the rest of this questionnaire

   Had your Mobility:   Improved ☐ Deteriorated ☐ Stayed much the Same ☐
   Had your Care Needs: Improved ☐ Deteriorated ☐ Stayed much the Same ☐

Is there anything you would like to clarify, or information to share re the option you have chosen above? Or, if none of the options 1-7 above are suitable, please describe your situation re DLA & PIP here.

...........................................................................................................................................................................

...........................................................................................................................................................................

...........................................................................................................................................................................

Q2. DISABILITY LIVING ALLOWANCE

What was the outcome of your most recent DLA application / assessment?

Mobility Component (please circle) High / Low / None
Do you agree that this was the correct rate of mobility component? ☐ yes ☐ no

Care Component (please circle) High / Middle / Low / None
Do you agree that this was the correct rate of care component? ☐ yes ☐ no

Was this DLA award:

For a Fixed Term ☐ if so, for how long? ..........................................................................................................
Indefinite ☐
Q3. WHAT STAGE OF THE PIP ASSESSMENT PROCESS ARE YOU AT?

*please tick as many as apply to you....*

- [ ] 1. I have received a letter to say my DLA is stopping and I can claim PIP
- [ ] 2. I have received a PIP2 ‘How Your Disability Affects You’ questionnaire to complete but not yet returned it
- [ ] 3. I have returned a PIP2 ‘How Your Disability Affects You’ questionnaire but not yet had a decision
- [ ] 4. I have received a decision on my PIP claim
- [ ] 5. I have been assessed for PIP and am now being reassessed/have been reassessed

*If this applies to you, please complete this questionnaire regarding your first PIP assessment.*

Please provide any further information or clarification about the stage of PIP process you are presently at here:

........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

Q4. COMPLETING THE PIP2 ‘HOW YOUR DISABILITY AFFECTS YOU’ QUESTIONNAIRE

a. TIMESCALE TO COMPLETE PIP2

Was the timescale specified long enough for you to complete the form?  
[ ] yes  [ ] no

If not, did you make contact to say that you needed more time?  
[ ] yes  [ ] no

If you did, what response did you receive?
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

Did you manage to submit a completed PIP2 form within the timescale given?

- [ ] yes
- [ ] no, submitted completed form, late
- [ ] no, submitted incomplete form, on time
- [ ] no, did not submit the PIP2 form at all

If you did not return a fully completed PIP2 form on time, you can tell us more here. For example, did this affect your PIP claim? In what way?
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

b. ASSISTANCE TO COMPLETE PIP2

Did you wish or require assistance with PIP2 completion?  
[ ] yes  [ ] no

If you completed the PIP2 form on behalf of the person with severe ME –

Did you wish or require assistance with PIP2 completion?  
[ ] yes  [ ] no

If you have answered ‘yes’ to either of the above:

Were you able to access assistance?  
[ ] yes, I received the help I was looking for
- [ ] yes, I received assistance, but limited
- [ ] no

Was the assistance:

- [ ] by home visit
- [ ] by going somewhere for help e.g. CAB office
- [ ] remotely i.e. by phone, e-mail, internet etc

What type of assistance did you receive?  ..............................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

How helpful was this assistance?  ..........................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
c. SUPPORTING EVIDENCE FOR PIP
Did you seek supporting evidence for your PIP claim?    ☐ yes    ☐ no
Did you submit supporting evidence with your PIP2 form? ☐ yes    ☐ no

If so - did you submit document(s) you already had?    ☐ yes    ☐ no
please specify: .........................................................................................................................
- did you submit document(s) obtained specifically to support PIP claim? ☐ yes    ☐ no
please specify: .........................................................................................................................

Please tell us more about this. For example:
If you requested medical evidence from your doctor – was it made readily available to you? was there a charge? Was it helpful? Did you decide not to submit certain ‘evidence’ because it did not appropriately support your case? Did you submit evidence / further evidence at a later stage?
...........................................................................................................................................................................
...........................................................................................................................................................................

Q5. ASSESSMENT BY A HEALTHCARE PROFESSIONAL

a. Did you state on your PIP 2 form that face to face assessment would need to be carried out at home?   ☐ yes    ☐ no

If so – how did the DWP / assessing agency respond? ..............................................................................................................
...........................................................................................................................................................................

b. Where did your face to face assessment take place?  ☐ at an assessment centre  ☐ at home  ☐ did not have a face to face assessment

c. Was the person who carried this out
☐ a doctor?    ☐ some other medical professional?  ☐ don’t know/can’t remember

d. Approximately how long did the assessment last? ..............................................................................................................

Q6. THE OUTCOME OF YOUR PIP CLAIM

a. What was the decision on your PIP claim?

Mobility Component (please circle)   Enhanced / Standard / None / Awaiting Decision
Did you agree with this decision on mobility component?    ☐ yes    ☐ no

Daily Living Component (please circle)   Enhanced / Standard / None / Awaiting Decision
Did you agree with this decision on care component?    ☐ yes    ☐ no

b. Duration of award       If you were awarded PIP: How long for? ..............................................................................................................
Q7. CHALLENGING PIP DECISIONS

If you disagreed with the decision reached by the DWP on your PIP claim -

a. Did you challenge the DWP decision?  [ ] yes  [ ] no

If you did: The first stage is ‘mandatory reconsideration’ by the DWP. What was the outcome of this?

Mobility Component  Decision Changed  [ ] yes  [ ] no  [ ] haven’t heard yet

If ‘yes’: changed to  (please circle)  Enhanced / Standard / None

Did you agree with this decision on mobility component?  [ ] yes  [ ] no

Care Component  Decision Changed  [ ] yes  [ ] no  [ ] haven’t heard yet

If ‘yes’: changed to  (please circle)  Enhanced / Standard / None

Did you agree with this decision on care component?  [ ] yes  [ ] no

How long did it take the DWP to carry out their reconsideration? .................................................................

If you are presently awaiting the outcome, how long have you been waiting? ..............................................

If you disagreed with the ‘mandatory reconsideration’ decision -

b. Did you lodge an Appeal?  [ ] yes  [ ] no

What was the outcome of your Appeal?

Mobility Component  Decision Changed  [ ] yes  [ ] no  [ ] haven’t heard yet

If ‘yes’: changed to  (please circle)  Enhanced / Standard / None

Did you agree with this decision on mobility component?  [ ] yes  [ ] no

Care Component  Decision Changed  [ ] yes  [ ] no  [ ] haven’t heard yet

If ‘yes’: changed to  (please circle)  Enhanced / Standard / None

Did you agree with this decision on care component?  [ ] yes  [ ] no

If an appeal has taken place, please tick as many as apply:

[ ] I attended
[ ] a family member or friend attended
[ ] a representative – e.g. a Welfare Rights Officer – attended
[ ] no one attended an Appeal Hearing – case was decided on the paperwork

How long did it take for your case to come to appeal? .........................................................................................

If your appeal has not yet taken place, how long have you been waiting? .........................................................

Is there more you would like to say about the PIP decision? about why you did or did not challenge it? about awaiting the hearing? or the conduct of the hearing? about help to prepare an appeal? or representation at the appeal?
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................

PIP REASSESSMENT

If you have had more than one PIP assessment: please tell us briefly about your reassessment for PIP:
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................
........................................................................................................................................................................