

Written evidence the Long Covid Support (HAB0126)

Long Covid Support:

Long Covid Support is a UK based charitable organisation. Long Covid Support (longcovid.org) runs an international peer support and advocacy group for people with Long Covid (pwLC). We provide online support for over 48,500 members in 100 countries/territories and advocate for people with Long Covid in the UK. We comprise a core group of 40-50 pwLC working across numerous work streams including advocacy, support, research involvement and un/employment rights.

Subgroup Employment Group:

This latter group emerged as we became aware of the considerable numbers of people with Long Covid who were of working age and unable to work as they did pre-Covid infection with an increasing need for benefit claims such as PIP and ESA.

About the Group members:

The employment group members are all living with Long Covid and come from a diverse range of professions including Occupational Health, Occupational Therapy, Physiotherapy, Nursing, Pharmacy, Union Representation, Human Resources and Business Management. Some of us have experience of job loss and claiming benefits in addition to supporting our members with associated challenges.

Long Covid

Definition

Long Covid is an umbrella term in common usage; adopted initially by patients,¹ then accepted by the NICE review ² to define persistent symptoms that can affect individuals' organs with multi system involvement that lasts longer than 12 weeks after an acute post COVID -19 infection.³ Common symptoms of Long Covid include debilitating fatigue (energy limitation) impacting every aspect of daily life. Symptoms may be brought on by physical, mental, social, and emotional exertion during or sometime after activities.⁴

The World Health Organisation, while acknowledging the common patient usage of "Long Covid", has agreed its own terminology for the condition, "post-Covid condition", adopted by Delphi consensus on 6 October 2021.⁵ The lack of empirical research on this new condition means there is still a limited understanding of this

condition and individuals with Long Covid often present with their own unique combination and range of symptoms, although an unpredictable pattern with relapses and fluctuations that wax and wane is typical.

Despite some positive developments in relation to the diagnosis, treatment and management of Long Covid,⁶ many unknowns remain. Many patients report ongoing problems receiving a diagnosis; inequitable access to Long Covid clinics, patchy and variable offers of healthcare provision. These challenges and delays in diagnostics and treatments may mean that the medical information a patient with Long Covid can provide as evidence for a benefit claim is sparse at best. Thus, questions are raised about how the Department can accurately assess an individual's entitlement to benefits.

Introduction

We welcome this opportunity to inform the Work and Pensions Committee of our serious concerns about the barriers, and poor experience and assessment outcomes pwLC and their families (including those that have children with Long Covid) have had when applying for PIP, ESA and UC. We have responded to questions (1,3,4,8,9,13,14) and drawn on evidence submitted to the Parliamentary Inquiry on Employment Support in June 2021⁷ and response to the Shaping Future Support: The Health and Disability Green Paper in October 2021.

There are 1.3 million people living with Long Covid in the UK ⁸ Many of these pwLC are facing significant financial hardship, either as individuals and/or as parents with children with Long Covid due to job loss * and the extra costs associated with having a long-term condition and disability. Therefore, timely and easy access to support to social security benefits is vital and delays and denials to such benefits are impacting on pwLC's recovery, physical and mental health, and wellbeing. We are extremely concerned that the Department is not recording Long Covid for peoples' claims ⁹ and the implications of this are wide reaching. This must be urgently corrected.

Barriers for people with Long Covid (pwLC) reported to our group in claiming PIP and ESA include:

- Not being made aware of their entitlement to PIP/ESA/UC (e.g., not being informed about these by healthcare professionals)
- Not understanding if they are eligible for PIP/ ESA/UC *
- Self-questioning- am I ill enough to claim benefits?
- Self-questioning eligibility for PIP - am I disabled and will my symptoms last 12 months or more?
- Having limited or no access to advocacy in completing the application process
- Feeling distrustful of the DWP
- Being fearful or worried about claiming benefits
- Being too unwell to make a claim or seek support to do so *
- Having limited energy and or cognitive dysfunction to complete the application process (e.g., forms) and gain supporting evidence (therefore weighing up is the effort worth it if I am unlikely to be awarded the benefit)
- Concerned that the impact of their Long Covid symptoms will be disbelieved
- Struggling to detail and document the full extent of their illness
- Fearing they will be assessed inaccurately and made to look for work

incompatible with their health

*Findings from our Long Covid Support Survey in 2021 N=252

17% of respondents to our survey had lost jobs via dismissal, resignation, redundancy or medical retirement, with a further 1.5% retired. 65% of respondents had not yet claimed any form of benefits. Of the people citing factors that stopped them applying, 46% were unsure if they were eligible and more than one in five found the process confusing and overwhelming. Consequently, some pwLC are experiencing significant financial hardship. This also reveals that some people who are not claiming benefits will be missing out on their NI contributions and state pension. 70% of the respondents in our survey wanted the assessment questionnaires to be simpler and shorter with 35% requesting digital forms.

1. 1. How could DWP improve the quality of assessments for health-related benefits?

There is a concern that supporting evidence provided by a claimant i.e., from others involved in their care or significant others is not being considered or disregarded in the decision-making process for pwLC.

The process from the outset is considered hostile. Shown in comments from our survey: *“When brain fog and fatigue are a big problem, filling a 40-page form caused great anxiety and exhaustion”*

“Questions difficult as symptoms are different most days”

3. Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?

No. The PIP descriptors do not accurately assess functional impairment for pwLC. This assessment is not fit for purpose and must be changed to accurately consider:

- the significant number of Long Covid related symptoms that can be experienced (i.e., there are at least 200 symptoms that have been identified¹⁰) and the cumulative impact these may have on an individual's ability to undertake daily activities of living. Therefore, it is vital to ascertain whether the Department acknowledges and recognises the wide range of Long Covid symptoms and makes this explicit in its guidance to contractors' medical assessors and its own decision makers.
- the fluctuating and episodic nature of Long Covid ⁴ It is not as simple as an assessor asking a pwLC whether they have 'good or bad' days, because a person may be able to function in one activity for part of a day, but then be unable to repeat that activity safely and reliably later that day or again the following day.
- Considers episodic disability when assessing function in mobility and activities of daily living. For example, when asking a person about how far they can walk, they should ask if this is consistently reproducible in a safe way without impacting symptoms or function later that day or in the following days.
- Post exertional malaise (PEM) and post exertional symptom exacerbation (PESE), which means that an activity may be undertaken by a pwLC, but

they may then experience an exacerbation of their symptoms that same day or in the following days. ¹¹ Also see the work of Chronic Illness Inclusion and reference to 'payback'. ¹²

- Adequately consider the impact of a pwLC's mental health on their activities of daily living.
- Adequately consider the impact of a pwLC's cognitive dysfunction on their activities of daily living.

Furthermore, it is evident that the PIP descriptors omit to ask questions about how a person undertakes certain essential activities of daily living such as food shopping, washing up after a meal, housework, and laundry. Therefore, the current questionnaire and medical assessment do not reflect or take into consideration the full range of activities a pwLC needs to undertake to live an independent life. PIP is likely to be essential to many pwLC to support the additional and unexpected costs associated with managing multiple symptoms that extends to the workplace too. For example, seeking alternative ways to undertake activities of daily living such as shopping e.g., online shopping delivery charges, taxis to shops or use of aids and equipment that will enable pwLC to better manage for example by conserving their energy and reducing fatigue.

- Given many pwLC have been unable to access a Long Covid clinic and there are challenges and constraints with GP appointments, they are typically having to self-manage their symptoms in the absence of medical support. Therefore, we need to ascertain whether medical assessors and decision makers are making incorrect clinical judgments about any claimants who have had little or no treatments e.g. a claimant may have not been prescribed medication for their low mood or pain or had any investigations or rehabilitation.
- There are serious risks in assessors making clinical reasoning statements in PIP reports such as '*you are able to drive a car showing adequate cognition and concentration*'. A pwLC may interpret this statement as fact, and assume they are safe to drive when they may have concentration problems, cognitive fatigue, vision problems and not been assessed e.g., for cognitive dysfunction or undertaken an assessment to determine their safety when driving.
- Similarly medical assessors are potentially making unsafe and dangerous clinical judgements when assessing a pwLC's reported low mood, e.g., if an assessor documents that "*no audible signs of low mood or anxiety were noted*" during a telephone assessment. This does not mean that a pwLC was not experiencing low mood or suicidal thoughts and any observable signs could be hidden during a telephone call.

4. Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?

The descriptors for ESA do not accurately assess claimants' ability to work. There are similar problems as already highlighted about the PIP descriptors above that need to be considered here. This assessment is not fit for purpose and must be changed to accurately consider:

- All the usual activities a pwLC is usually required to do outside of work and while in work, such as getting washed and dressed, preparing food, travelling to and from work within the context of their energy impairment and Long Covid symptoms.
- The fluctuating and remitting nature of Long Covid symptoms and recognise that there may be times when people can work and times when they are less able to.

Guidance to how the impact of recurring and relapsing conditions and cumulative impact of symptoms is assessed can be found in sections C and D of the 2011 Guidance of the definition of disability under the Equality Act 2010 These should be applied to Long Covid.

The onus on providing evidence to support a claim should not fall to the individual, and there needs to be a review of the best way to gather this for pwLC. Better quality evidence is likely to be beneficial in the decision-making process for PIP and the WCA and adopting a holistic approach is important. However, given that large numbers of people with Long Covid are still waiting to access specialist healthcare services as well as diagnostic tests, investigations, treatment and rehabilitation. There may be a lack of evidence available to support our claims and this may lead to inaccurate decisions and consequently stressful mandatory reconsiderations and appeals or unacceptable lengthy waits for a decision.

We recommend that the Department:

- Reviews the PIP and WCA assessments to ensure that the assessment is holistic and considers how a pwLC's symptoms impact on their ability to carry out all their required daily activities throughout a day and the following days. These assessments are not fit for purpose and fail to consider the cumulative effect of having to undertake a range of activities that may need to be repeated during a day. In addition to whether a pwLC can carry out their activities safely and reliably. To manage symptoms pwLC need to take quality rest periods which requires daily planning, and prioritisation of what activities can be undertaken, when and how.¹³ Such planning includes all daily activities of living and those associated with paid work or work preparation. If PIP is awarded, this benefit can also be useful to enable pwLC to delegate tasks e.g., by paying for a cleaner or shopper and conserving energy for other activities. Pacing of activities is crucial for pwLC to reduce the risk of PEM/PESE that can be experienced especially if an individual pushes beyond their 'energy envelope'.¹¹
- Urgently provides training to healthcare professionals who contribute to the assessment process and disseminate updated medical knowledge about Long Covid. This was featured prominently in responses to our Long Covid Support survey.
- Consider the roles of carers in the assessment process. We are aware of the considerable support many people with Long Covid are receiving from family members who have had to take on the role of a (paid or unpaid) carer.

It may be more appropriate for an individual to complete a diary to reflect the nature of their Long Covid symptoms over a set period to discuss at a medical assessment.

6. How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?

Benefits: Saves an individual's effort in having to undertake the medical assessment.

Drawbacks: Risks if a clinician does not have the required expertise, knowledge, and skills to understand the complexity and full impact of Long Covid on an individual's daily life. There may be insufficient evidence available to a clinician.

7. Appeals data shows that, for some health-related benefits, up to 76% of tribunals find in favour of the claimant. Why is that?

A What could DWP change earlier in the process to ensure that fewer cases go to appeal?

Gaining evidence from healthcare professionals involved with a claimant is crucial however, there are specific challenges for pwLC example,

- As stated above many pwLC have minimal input from healthcare professionals and may have limited time to discuss all their Long Covid symptoms with a GP.
- It is unclear whether the DWP contacts any or all the stakeholders documented on a claimant's form who can provide evidence. In addition, there are questions as to whether these stakeholders have current health related information (e.g., with the lengthy delays in the claims process).

8. Is there a case for combining the assessment processes for different benefits? If not, how else could the Department streamline the application processes for people claiming more than one benefit (eg. PIP and ESA)?

There is a need to streamline the application process for a claimant if they are claiming both PIP and ESA. However, there are risks of combining these assessments, and PIP must remain non means tested and to still be awarded to pwLC who are also in work. A more efficient and cost-efficient process needs to be explored. But it is vital that if a combined assessment is undertaken that a person is not put at risk of harm e.g., in experiencing PEM/PESE if a combined assessment results in a longer assessment duration.

9. What are your views on the Department's "Health Transformation Programme"? What changes would you like to see under the programme?

More than 70% of respondents to our survey wanted to see shorter, simpler application forms and more than 35% wanted forms to be digital. A third also wanted to see a simpler appeals process.

a. (For people claiming) Would you like to be able to manage your benefit claim online?

More than 35% of respondents to our survey wanted application forms to be digital. And more than half wanted supporting medical evidence to be available and accessible in one place.

1. 1. What would be the benefits and drawbacks of DWP bringing assessments “in house”, rather than contracting them to external organisations (Capita, Atos and Maximus)? In particular, would this help to increase trust in the process?

There is a legacy and ongoing mistrust in terms of the Department and its external contractors. There is a general perception that assessors are not suitably qualified and not knowledgeable about recurring and relapsing medical conditions in particular, and that verbal responses to assessment questions are misinterpreted. The lack of accountability by outsourced assessors creates a perception of a hostile and unaccountable system. This may be resolved by bringing assessments in house.

Benefits:

It would give the Department control over the level of expertise and appropriate training of assessors. It would reduce the widespread perception that contracted assessors are motivated by profit in maximising application rejections and not by public interest or the welfare of claimants. It could control how information is recorded to ensure it is accurate and truthful and be accountable when it is not. Accountability would improve trust.

79% of respondents to our survey said applying for benefits would be made easier by having assessments that reflect the relapsing nature of Long Covid and better decision-makers' understanding of Long Covid.

Drawbacks:

This would depend on how these assessments were carried out.

The impact of assessment/application on claimants

13. DWP recently published research on the impact of applying for PIP or ESA on claimants' mental and physical health. What would be the best way of addressing this?

Our data gathering both formal and informal matches many of the findings in this research cited by the Department. The current questionnaires for PIP and ESA are not fit for purpose and not designed to capture the impact of Long covid on an individual's daily life.

20% of our respondents found the application process too difficult. Comments such as “*Lots of questions that you have to fill out on paper, and I cannot concentrate for long periods of time. They also ask you to come in for a health visit at some stage*”

and I am housebound so find it incredibly difficult to leave the house.”

Furthermore, physical, and mental health of people with long Covid is negatively impacted by ignorance of their condition and mistrust. There needs to be a presumption of honesty. Our surveys have shown that far from wanting to claim benefits while well, newly disabled people find the process traumatic, stigmatising, and embarrassing — they would not put themselves through it in bad faith.

We are starting to see the significant financial impact of Long Covid on peoples’ daily lives including members reporting they are facing homelessness and bankruptcy. We recommend that the Department urgently review its processes and ways of working to ensure their duty of care is not compromised for disabled pwLC. This is especially important given the numerous concerns have already been raised for example see.

14

We are aware of pwLC having suicidal ideation and although a sensitive subject, we have also had reported cases of suicide within the Long Covid community. Therefore, the Department must ensure that it reviews its safeguarding measures, to meet its duty of care and does not fail to provide pwLC with their basic human rights to shelter, warmth and food.

Experiencing the realisation of the extent of their illness (e.g., this may be first time they have listed all their Long Covid symptoms and the impact on their daily life) This may be traumatising and the fear of not being awarded a benefit is likely to be extremely stressful which again will have a substantial impact on a pwLC’s physical and mental health and wellbeing and recovery.

We agree with the option to extend the deadline for applications that was highlighted in this research, but we feel strongly that the onus on providing much of the evidence to support claims should rest with professionals involved in the individual’s claim. In addition to evidence statements by other stakeholders such as family members. Administrative related tasks are considerably energy and cognitively demanding for many pwLC.

The Department must ensure pwLC can have trust in being believed when they report on the impact of their symptoms to assessors and front-line staff. Unfortunately, there are too many reports of people with Long Covid experiencing disbelief of their illness in both health and work settings. ¹⁵

Due to the impact and nature of Long Covid symptoms the current process for claiming PIP and ESA is too lengthy, complex, and challenging for many people. Reports from our Long Covid community reveal the significant stress, anxiety, and disrupted sleep that the application process and procedures can cause. These factors can then impact on a person’s recovery from Long Covid. ¹⁶

Discrepancies between what a claimant verbally reports during an assessment and what an assessor documents are commonly reported by pwLC to the Long Covid Support Employment Group. This can cause considerable upset and anger especially if a benefit has not been awarded.

We are concerned about the negative impacts pwLC’s physical and mental health when they are not awarded PIP and need to request a mandatory reconsideration or appeal.

Waits for assessments

14. What could the Department do to shorten waits for health-related benefit assessments—especially for ESA/UC?

The Department must set agreed time frames to respond to any decision making and address the lengthy delays in waiting for claims to be processed. There is evidence that the average claim takes several months to be processed by the Department and our Long Covid Support survey revealed waiting times up to eight months with appeals. These are unacceptable delays which expose pwLC to significant financial hardship which can impact on recovery, physical and mental health, and wellbeing. Similarly, the lengthy delays for medical assessments and decisions on claims is unacceptable and impacting on the health and wellbeing and recovery of people with Long Covid and their families. For example, we have examples of people waiting five months for a PIP assessment and then two months for a decision. The maximum length of time from application to final decision in our survey was approaching a year. Further waiting time is then required for a mandatory reconsideration (we are hearing reports of up to ten weeks) and appeals.

Policy development

16. How effectively does DWP work with stakeholders—including disabled people—to develop policy and monitor operational concerns about health-related benefits? a. What steps could the Department take to improve its engagement with stakeholders?

It is crucial that both the Department and its contractors, who undertake the medical assessments, proactively seek to engage with the Long Covid community i.e., disabled people and disabled people led organisations that have evolved during the pandemic such as Long Covid Support. At present we are typically hearing of stakeholder events via our collaborations for example, Chronic Illness Inclusion and our proactive surveillance of social media which of course demands our energy. Therefore, the Department needs to ensure that there are accessible methods of engaging pwLC and groups such as our Long Covid Support Employment Group who cannot only carry out surveys but importantly disseminate information within the wider community.

There needs to be a transparent and straightforward process for pwLC to feedback concerns about their medical assessment experiences. Anecdotal reports from pwLC show it is apparent that there is a need to train and educate all healthcare professional assessors about the lived experience of Long Covid. This is essential in terms of how assessments are conducted, and answers interpreted along with assessors' awareness when further prompting of details is required in medical assessments.

Summary

The Department should seek to improve the experience of the benefit system to better meet the needs of pwLC and ensure that the process does not have an adverse impact on their physical or mental health and wellbeing or hinder recovery. Social security benefits are crucial to support many pwLC. Therefore, we urge the Department to remove the barriers within the application process (including offering advocacy as standard), changing the assessment questionnaires and medical assessments that are not fit for purpose for pwLC.

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