

ENDOMETRIOSIS AND THE BENEFITS SYSTEM

Endometriosis is a disease affecting 1 in 10 women and those assigned female at birth from puberty to menopause, although the impact may last for life. It is a disease, where cells similar to those lining the womb (uterus) grow elsewhere in the body. Common symptoms include chronic pelvic pain, painful periods, pain during or after sex, painful urination and bowel movements, fatigue and difficulty getting pregnant.

Endometriosis symptoms vary from one individual to another; some may have minimal symptoms, whereas for others endometriosis can be debilitating. Symptoms can fluctuate depending on the menstrual cycle, so some will have much worse symptoms at certain times of the month. However, other can have significant symptoms all the time. Those with debilitating endometriosis can find themselves unable to work and struggling to carry out normal every day living tasks, thus requiring assistance from the benefits system, specifically claims for disability benefits like Personal Independence Payments (PIP).

For many with endometriosis, the symptoms experienced and impact of surgery result in disability, meeting the definition of disability under the 2010 Equality Act as it is a physical impairment, and can have a substantial and long term negative effect on ability to do normal daily activities¹. Endometriosis may also fall under the special rules related to fluctuating and recurring conditions, addressed in guidance on the definition of disability in the Equalities Act². The potential fluctuating nature of symptoms experienced must be considered when determining impairment in line with the relevant DWP guidance².

OUR RESPONSE TO INQUIRY QUESTIONS

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

Anyone applying for health-related benefits must be assessed by an assessor who has specific knowledge and understanding of the condition being assessed. This is essential to ensure an accurate and fair assessment of an individual's health and ability to undertake work or daily living activities.

Sadly, we have heard from the endometriosis community this this does not always happen and assessors sometimes lack even basic knowledge of endometriosis. This can lead to those who are disabled due to endometriosis and struggle to carry out daily living activities being incorrectly told that they do not qualify for any support. In addition, there are those who do not even apply in the first place, not understanding that endometriosis may be considered a disability, so believing they are ineligible.

In the 2020 inquiry of the All Party Parliamentary Group on Endometriosis³, those with endometriosis who applied for disability benefits reported incidents where they had been assessed by someone who did not understand endometriosis:

"The process is very difficult and often you are assessed by health care professionals who have no knowledge on the condition"

¹ [Definition of disability in the 2010 Equality Act](#)

² [Equality Act 2010 - Guidance on matters to be taken into account in determining questions relating to the definition of disability](#), Office of Disability Issues, May 2011.

³ [Endometriosis in the UK – Time for Change](#), Inquiry Report of APPG on Endometriosis, October 2020

“They just say it's a period and tell us we only get pain during a period, or they know nothing about the condition”

In particular, there were cases where the assessor demonstrated that they did not understand that endometriosis is fluctuating and recurring condition, which goes against the guidance².

“Endometriosis does not mean the same symptoms every day, and if you have your assessment on a better day, it shouldn't mean it affects how benefits are distributed. Awareness of endometriosis by those assessing your benefits is key”.

One respondent assumed that because endometriosis is not listed in the relevant guidance, that means it is not classed meeting the definition of disability:

“And since endometriosis is not in the list, I understood is that it is not recognised as a disability.”

There were a number of respondents to the 2020 APPG inquiry³ who informed us that they had been told by DWP staff/contractors that endometriosis was not considered to be a disability and they could not apply for health related benefits:

“I have been told endo is not classed as a disability, so I have no grounds to apply for any help”

“I have never applied due to being told it was not an option”

“Unfortunately applying for PIP has got me nowhere; they don't count endometriosis as a disability”

This shows a lack of understanding both of endometriosis and of the definition of disability under the Equalities Act and highlights the importance of those with endometriosis being assessed by assessors with good understanding of the condition.

We recommend that DWP:

- Ensure guidance to all assessors states that endometriosis may result in disability.
- Ensure that all assessors who deal with claims from those with endometriosis have undergone training to ensure they have sufficient knowledge of the condition to undertake a fair and accurate assessment.
- Update the guidance on the Equalities Act to specifically mention endometriosis as an example of a fluctuating and recurring condition that may result in impairments that meet the definition of disability.
- Ensure that DWP staff and contractors understand how endometriosis meets the definition of disability in the Equalities Act.

a) Have you seen any specific improvements in the process since the Committee last reported on PIP and ESA assessments, in 2018?

No comment.

2. Are there any international examples of good practice that the Department could draw on to improve the application and assessment processes for health-related benefits?

No comment.

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

Assessing functional impairment for a fluctuating and recurring condition like endometriosis must be considered as per the existing guidance, so it takes account of the entirety of the individual's experience of endometriosis.

Some with endometriosis will experience symptoms most or all of the time. Others may experience debilitating symptoms at different times through the month. Severity of symptoms may vary. Should the assessment be based only a day when symptoms are not at their most severe, this will give an inaccurate and unfair assessment of overall health and disability.

Comment from inquiry respondent:

"Some days are better than others, but that is not taken into account when going for assessment"

We therefore recommend:

- Assessments of individuals with fluctuating conditions allow for answers reflecting the difference in severity of symptoms and ability to undertake tasks at different times.

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

As mentioned above for PIP assessments, ESA capability for work assessments need to allow provision for those with fluctuating and recurrent conditions to give answers reflecting the difference in severity of symptoms and ability to undertake tasks at different times. This is necessary in order to accurately reflect their overall health, disability and ability to undertake tasks.

5. DLA (for children under the age of 16) and Attendance Allowance usually use paper-based rather than face-to-face assessments. How well is this working?

No comment.

- a. Before PIP replaced DLA for adults, DLA was also assessed using a paper-based system. What were the benefits and drawbacks of this approach?

No comment.

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?

The benefit of this approach would be that a treating clinician will have specialist clinical knowledge and understanding of endometriosis including the debilitating and fluctuating nature of the condition. Such a clinician will be better positioned to give a long-term view of the individual's health than an assessor who lacks understanding of the condition.

This can help avoid inaccurate and unfair assessments, which then result in an individual not receiving benefits they are entitled to receive and/or having to go through an appeal in order to receive them. Appeals are costly for the Department of Work and Pensions as well as stressful for the claimant.

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

We have heard of claimants with endometriosis who had to go to tribunal in order to have their claim accepted. Comments made by respondents to the 2020 APPG inquiry³ about being assessed by assessors who

did not understand endometriosis, recognise fluctuating conditions, or believe their level of symptoms, may explain some of the initial refusals that are later reversed at tribunal when the claim is correctly assessed.

This highlights the importance of undertaking the health benefit assessment correctly in the first place so that the right decision is arrived at without the need for appeal. Part of the solution to this in endometriosis is ensuring that assessors who will assess claimants with the condition have good understanding of the condition and if they do not, training should be mandatory before they assess any such claims.

Some comments from respondents who had their claims refused:

"I am currently in the LCWRA category of Universal Credit. I had to take this decision to a Tribunal after a 'health professional' (actually a male sports physiotherapist) dismissed the limitations of my endometriosis, bowel and bladder prolapse, incontinence and severe chronic pain. I am currently in the Process of applying for PIP, but receive no other financial support whatsoever."

"When I was in difficulty Universal Credit did not consider endometriosis as a disability. It was obvious no help will come from them."

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

When assigning cases to assessors, this is either done on the basis that the assessor has sufficient knowledge of the medical condition concerned, or will have to undergo training before the assessment takes place.

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)?

No comment.

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

No comment.

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

No comment.

- b. 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?

No comment.

10. What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments?

No comment.

- a. Is there a case for making some of the changes permanent?

No comment.

11. Most assessments for Industrial Injuries Disablement Benefit were suspended during the pandemic. What has been the impact on people trying to claim IIDB?

No comment.

a. Some IIDB claimants will receive a lower award than they might have, due to the suspension of assessments, because IIDB awards are linked to age. Should the Department compensate these claimants? How?

No comment.

b. What lessons could the Department learn for how it deals with these claims in future, in the event of further disruption to normal services?

No comment.

12. DWP believes that applications for some benefits dropped sharply at the start of the pandemic because claimants weren't able to access support (for example, from third sector organisations) to complete their applications. What are the implications of this for how the Department ensures people are able to access health-related benefits consistently?

DWP can ensure that guidance for applicants is easily available, accessible, and that there is guidance suitable for different audiences. Additionally, including examples for those with fluctuating and recurring conditions like endometriosis so they understand that they are able to apply.

a. How can the Department best help the third sector to support claimants in their applications?

The Department could work with Endometriosis UK on guidance for applicants with endometriosis and also review how staff are trained to ensure they can accurately and fairly undertake health assessments on those with endometriosis.

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?

Respondents to the 2020 survey found the following to be detrimental to mental health:

- Having their claim rejected leading to feelings of their disability not being believed
- The stress of having to appeal
- Financial worries due to claim being refused

Comments from respondents included:

"Stressful and upsetting. I had to go to tribunal to get my PIP accepted."

"It took over 2 years for me to receive the correct amount of financial support and I would have found it incredibly difficult to have gone through the process without significant support from my mother."

"Was the most awful thing I have been through for nothing, couldn't cope with appealing it was too distressing"

This can be addressed by having claims accurately assessed in the first place thus reducing the number of incorrectly rejected claims. In addition, training for assessors in relation to how questions are asked, and how rejection of a claim is communicated etc could help in relation to reassuring claimants that they are not being wholly disbelieved.

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

No comment.

a. How effectively does the “assessment rate” for ESA cover disabled peoples’ living costs while they wait for an assessment? Is there a case for introducing an assessment rate for other health-related benefits?

No comment.

15. The Scottish Government intends to introduce its own assessment process for the Adult Disability Payment, which will replace PIP in Scotland from 2022. What could DWP learn from the approach of the Scottish Government?

No comment.

a. PIP started rolling out in Northern Ireland in 2016. Is there evidence that the Department learned from the experience of rolling out PIP in the rest of the UK?

No comment.

16. How effectively does DWP work with stakeholders—including disabled people—to develop policy and monitor operational concerns about health-related benefits?

No comment.

a. What steps could the Department take to improve its engagement with stakeholders?

In the case of those with endometriosis, the Department could work with Endometriosis UK on the development of guidance for applicants with endometriosis and training for those who assess claimants with endometriosis.

ABOUT US

Endometriosis UK is the UK’s largest charity supporting those affected by endometriosis. We provide information through [our website](#) and information leaflets, and direct support through a helpline, support groups, and an online forum. We raise awareness and campaign to improve the lives of all those affected by endometriosis, and are involved in research. We work closely with other women’s health organisations including RCOG and RCGP.

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