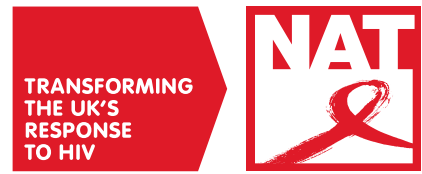




National HIV Nurses Association



Providing medical evidence for benefits applications: A guide for HIV clinicians

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The success of HIV treatment means that most people diagnosed today will not find their HIV a barrier to work or other daily activities. However, there are some who will still need to apply for support, for example those who were diagnosed late or diagnosed many years ago and those who are living with co-morbidities.

There are ongoing changes happening to the UK welfare benefits system and many people living with HIV will be affected. The evidence provided by clinicians and other care workers is crucial to the success or otherwise of benefits claims in the new system.

This is a guide for HIV consultants and specialist nurses who may be asked to provide medical evidence for patients in support of benefits claims.

Key benefits for people living with HIV

Over the past five years the Government has introduced new illness and disability-related benefits, replacing benefits which our patients have previously been able to access. In practice, this means that some people living with HIV may find it harder to be found eligible for these sorts of benefits. It also means that many people currently accessing benefits, including those with lifetime awards, will need to be re-assessed under the new system, in order to access support.

There are two main benefits that people living with HIV may need to apply for:

1. Employment and Support Allowance (ESA) has replaced Incapacity Benefit for people who can't work due to illness or disability.

ESA is now the benefit for anyone with HIV who is not fit for work due to poor health. People who are found eligible for ESA will be put into either the **'Work-Related Activity Group' (WRAG)** or the **'Support Group'**. Those in the WRAG will be expected to be able to move towards work in the near future (normally within 3–12 months) and will be encouraged to start thinking about looking for jobs. People who are in the Support Group are considered too ill or disabled to go into work in the foreseeable future.

The assessment for ESA is called the Work Capability Assessment (WCA) (see How people living with HIV will be assessed below).

2. Personal Independence Payment (PIP) is replacing Disability Living Allowance for people who need extra financial support due to health needs.

Ten percent of people accessing HIV care in the UK are currently in receipt of Disability Living Allowance (DLA), receiving an average of £103 per week.

DLA is being replaced by Personal Independence Payment (PIP). One of the main reasons for this change is to reduce future expenditure on this type of benefit. This means that PIP will be much more focused on people with more severe needs, and people with lower-level needs may not be found eligible for the benefit.

Like DLA, PIP is not an out-of-work benefit. Rather, it is designed to pay for the extra costs of living with a disability or long-term condition. You can claim PIP if you are in work, or out of work.

There are two types of PIP payment and someone living with HIV may get one or both. The **Care Component** is paid to people who have limited ability to perform the tasks of daily living such as bathing, dressing, preparing food and eating. The **Mobility Component** is paid to people who have trouble getting about. Both components are paid at either a 'standard' or 'enhanced' rate, depending on how severe the functional limitation is.

The Government has published a Guide to PIP for the healthcare professions: (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/303676/pip-quick-guide-health-professions.pdf).

How people living with HIV will be assessed

Both assessments are of 'functionality' – that is to say, the Department for Work and Pensions (DWP) does not take any interest in someone's primary diagnosis, only how it may affect their ability to perform day-to-day activities. This should inform the type of evidence you provide, if you are asked to provide evidence to support someone's claim.

ESA

The assessment for ESA is called the Work Capability Assessment or WCA. The WCA looks at a range of functions considered relevant to someone's ability to work including areas such as concentration, manual dexterity, mobility, any problems with continence and the ability to sit and/or stand. The WCA calls these functions 'descriptors' (see Appendix 1 for a full list of these).

It is important to keep these descriptors in mind when providing evidence to support a claim, as the benefits decision-makers are only interested in someone's functional ability against these specific activities. (The only exception is if someone is so ill or disabled that they would be likely to put their own health or someone else's health at risk if they were expected to work. If this is the case, for instance because of a severely compromised immune system or TB infection, mention it.)

When applying for ESA, the person living with HIV will firstly fill in a form explaining the difficulties they have with the activities covered by the descriptors. They will also provide medical evidence to support their claim, including any evidence you provide to them. If the form and evidence are not returned in time it may delay the claimant's access to support or lead to discontinuation of current benefits payments.

In most cases, the next step will be a face-to-face assessment with a contracted healthcare professional (at present someone employed by ATOS – the company who medically assess claims), who submits their findings to the DWP. This face-to-face assessment is also built around the functional descriptors and ‘points’ are allocated to indicate how severe the individual’s functional impairment is.

A DWP decision-maker looks at all the evidence provided and decides whether the individual is eligible for the benefit and if so, whether they should go in the WRAG or Support Group.

PIP

The PIP assessment is also based on a list of functional descriptors (see Appendix 2 for a full list of these). There is a list for the care component and another for the mobility component.

PIP applications start with a phone call, and then the applicant will be sent a form to complete. Unlike ESA, people applying for PIP are not expected to collect their own medical evidence. Instead, they are asked to provide contact details for relevant health and care professionals. The PIP assessment provider (ATOS or Capita) will approach as part of their assessment. However, the assessment process can be quicker and more accurate if the claimant additionally provides their own copies of pre-existing medical evidence – so some people living with HIV will choose to do this and may ask you for a letter or copies of notes.

People who are on DLA will not automatically be found eligible for PIP. They will have to be assessed under the new PIP criteria. People who are on long-term DLA awards will not need to go through the PIP assessment until after October 2015.

NAT have published a factsheet on claiming PIP for people living with HIV with more details of the timetable for PIP replacing DLA: (http://nat.org.uk/media/Files/Policy/2014/April_2014_PIP_Factsheet.pdf).

What information to include

When providing evidence, keep in mind whether the claim is for out-of-work support (ESA) or additional support with managing health needs (PIP). Also look at the descriptors used for the specific benefit so that your evidence is as relevant as possible (see How people living with HIV will be assessed and the appendices for more details).

For each benefit, you should usually provide the following:

- Clinical history: How long the claimant has lived with HIV, most recent CD4 cell count, viral load and antiretroviral medication (if taken).
- Details of any co-morbidities, co-infections or other long-term conditions you are aware of and relevant medication.
- Any symptoms or impairment which you are aware of which have an impact on function, capacity to work or quality of life (including side-effects of treatment).
- Description of any mental health problems which you are aware of.

Dos and Don'ts when providing evidence

Do: Decision-makers are not medical experts so it is helpful to explain what clinical indicators mean (e.g. what a very low CD4 cell count means in terms of immune function and any risk to the patient of being required to seek work).

Do: Try to avoid statements such as 'In my professional opinion this patient cannot work.' These assertions would need to be backed up with facts, for instance, 'In my professional opinion he is unable work due to HIV-related lipodystrophy, which has stripped the fat from his buttocks and lower limbs making it very uncomfortable and painful for him to sit for more than 15 minutes at a time.'

Do: Stick to what you know. A patient may mention an issue that they would like to be included in their medical evidence which has not previously been mentioned or documented. This could include common side-effects or symptoms for which they have been medicating with herbal or over-the-counter medications, for instance insomnia, constipation, diarrhoea. One option is to include in your evidence a statement such as 'During our most recent consultation, she stated that she is also currently experiencing lower back pain and haemorrhoids.'

Do: Be honest about the patient's abilities and general health. Benefits changes are a cause of anxiety for many but do not be tempted to exaggerate or embellish limitations to support an application. You need to be professionally accountable for what you write and your patient needs to be realistic about their capabilities. People who are found 'fit for work', and therefore ineligible for ESA, may still apply for Jobseeker's Allowance so would still be eligible for income support.

Don't: Use abbreviations without explaining these in full (e.g., VL, HCV).

Don't: List all past health problems without showing how these are relevant to current health. For example, 'When he was diagnosed he had PCP and oral candida which required hospitalisation' may have no relevance years later; however, a cancer, tuberculosis or hepatitis diagnosis may have some bearing on their current physical/mental health.

Some points to consider when providing evidence

■ **Be specific.** The most helpful evidence directly addresses the assessment criteria, which for both ESA and PIP look at claimants' ability to perform daily activities (see appendices for relevant criteria).

■ **Your evidence is key to support.** Benefits rules have become much more stringent and decision-makers' knowledge of HIV is often poor. If the application is refused because robust evidence was not provided someone can go to appeal. However, while waiting for an outcome they will not receive full benefits support, leaving your patient open to stress and poverty for weeks or months.

■ **It's not all about HIV.** For those who have multiple health issues, supporting letters should be sought from all involved in their ongoing care, e.g oncology, rheumatology, endocrinology, cardiology. Think about who provides psychosocial/emotional support, such as mental health services, drug and alcohol agencies, social services etc. Are these agencies providing letters to support this application?

■ **Some GPs will charge for medical evidence** so patients should only be advised to request GP letters if they have significant interaction with them. For PIP claims only, GPs will be reimbursed by the DWP for filling in their evidence form – but only when ATOS or Capita approaches the GP, not if the patient approaches them directly.

Examples of supporting letters

Bad example

The letter below simply states an opinion about capacity to work but does not provide any relevant evidence about functional ability. The Clinical Nurse Specialist (CNS) writing the letter would be relying on an out-of-date perception that people living with HIV should be eligible for benefits based primarily on their diagnosis.

To whom it may concern,

*Re: John Brown (13/12/1975)
Flat 1a, Kings Street, LONDON WC2 3NP*

I am writing to let you know that I believe that Mr John Brown should not be working or made to look for work. He has not worked for a significant period of time and would find it very difficult to secure employment at this stage. He is prescribed antiretroviral medication which can have side-effects which can restrict people's ability to work. I think it is unreasonable to expect him to be looking for work at this time, especially in this economic climate.

*Yours sincerely
Keith Smith
Clinical Nurse Specialist*

Good example

In this example, the CNS provides a detailed clinical history, plus up-to-date information on CD4 cell count and viral load and an honest assessment of what this indicates about current health. The evidence also includes information about key functional limitations caused by peripheral neuropathy and depression.

To whom it may concern,

*Re: John Brown (13/12/1975)
Flat 1a, Kings Street, LONDON WC2 3NP*

I am writing this letter to support Mr John Brown's ESA assessment. I have supported John as his Clinical Nurse Specialist for the past 3 years. His current health issues are as follows:

- HIV – John was diagnosed with HIV 13 years ago. He is under the care of Dr Green at Queen Mary's Sexual Health & HIV Centre. His initial CD4 cell (immunity) count was very low at 23, which indicated a severely depleted immune function. His most recent CD4 cell count is 455 and his viral load is undetectable (12/10/2013), indicating that his antiretroviral therapy is effective (see attached list for specific medications John is taking).*
 - Peripheral neuropathy – John has severe pain in his lower limbs. He is seeing Dr King's pain specialist team (who I understand will provide a separate letter). This pain affects his ability to walk or stand for extended periods. He walks with a stick and is taking several analgesics for pain control.*
 - Depression – John is supported by the community mental health team (they have been asked to provide a letter of support). He has a past history of depression and is taking antidepressants.*
- Due to John's chronic pain and depression I feel that he is unable to seek work. I am aware that he seeks support from the local HIV support agency where he takes part in the group work and has massage therapy for pain control.*

If you need any further information please contact me.

Yours sincerely

Appendix 1: Functions considered by the Work Capability Assessment (WCA) for ESA

Physical function descriptors

- Mobilising unaided
- Standing and sitting
- Reaching
- Picking up and moving or transferring by the use of the upper body and arms
- Manual dexterity
- Making self understood
- Understanding communication
- Navigation and maintaining safety
- Continence
- Consciousness during waking moments.

Mental, cognitive and intellectual function descriptors

- Learning tasks
- Awareness of everyday hazards
- Initiating and completing personal action
- Coping with change
- Getting about
- Coping with social engagement
- Appropriateness of behaviour with other people.

More detail: <https://www.gov.uk/government/publications/esa214-a-guide-to-employment-and-support-allowance-the-work-capability-assessment>

Appendix 2: Functions considered by the PIP assessment

Daily living descriptors

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

Mobility descriptors

- Planning and following journeys
- Moving around

More detail: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/259831/PIP-toolkit-factsheet-assessment-criteria.pdf