

HIV is a complex, lifelong condition and some people living with HIV experience extended periods of very poor health. Others live with long-term disabilities. Both can have a serious impact on day-to-day life - including finances. If HIV is having this sort of impact on your life, you might want to apply for welfare benefits.

This guide is about the two main disability benefits which you may need to claim:

**Employment and Support Allowance (ESA):** A benefit for people who cannot work due to disability and/or long-term serious ill-health.

**Personal Independence Payment (PIP):** A benefit which helps to pay for the extra costs of life with a disability and/or long-term ill-health. You can apply for PIP whether or not you are currently working. PIP is replacing Disability Living Allowance (DLA).

Both of these benefits are for people who are experiencing long-term, serious health problems. Only a minority of people living with HIV will be eligible. The Department for Work and Pensions (DWP) has an application process and criteria for each benefit. Before they approve you for either ESA or PIP, the DWP will need proof that your ill-health or disability has a severe impact on your daily life.

#### For both ESA and PIP, you need to do three things to make your application:

- 1. Fill in a form to explain why you need the benefit
- 2. Supply evidence about your health problems and/or disability
- 3. Have a face-to-face meeting with an independent healthcare worker (in most cases)

# This guide will help you with the second element - Sending in evidence about your health problems and/or disability.

The following are sources of information about the rest of the application process:

- -THT Direct: 0808 802 1221
- -Citizens Advice: www.citizensadvice.org.uk
- -Rights Net: www.rightsnet.org.uk

-Your local HIV support organisation: www.aidsmap.com/e-atlas

# **IMPORTANT:** If you don't do all three parts of the application, or you miss the deadline DWP have given you to complete your form, your ESA, PIP or DLA payments may stop – so always ask for help with your application, if you need it.

ESA and PIP have different assessment processes with different criteria. The next two pages explain the evidence requirements for these benefits. There is also information on what evidence you need to appeal a decision.

NAT and NHIVNA have also published a guide for healthcare professionals on providing evidence for patients who are living with HIV: www.nat.org.uk/media/Files/Publications/NHIVNA\_NAT\_FME-1.pdf



# **Employment and Support Allowance (ESA)**

#### Key points:

- You will need a medical certificate to start your ESA claim
- Send evidence about the work-related impact of your health problems with your ESA50 form
- Do not assume that the ESA assessor will contact your HIV doctor or nurse

#### What to send at the start of your ESA claim ...

When you phone up to claim ESA (or send in a form called the ESA1) you will be asked to provide a 'fit note'. This is a recent certificate from your doctor explaining that you are unable to work. Fit notes are usually written by GPs but can also be written by hospital doctors. You need to send it to start getting your ESA payments.

#### Things to send with your ESA50 form ...

Once you have started your claim you will be sent and asked to fill in the Limited Capability for Work Questionnaire (ESA50 form) with more details about your barriers to work and contact details for your healthcare professional/s. There is no guarantee that the ESA assessor will contact the preferred healthcare professional you nominate on your ESA50 form. So it is a good idea to get written evidence of anything which you want your HIV doctor or specialist nurse to say in support of your claim. Send this in with your form. You will also want to get written evidence from other healthcare professionals you see (e.g. psychologists, occupational therapists, liver specialists, cancer specialists).

#### What information to include ...

ESA is a 'functional' assessment. ESA assessors will not make a decision based on your HIV diagnosis - only the impact it has on your ability to work.

It is a good idea to show your doctor or nurse this list of activities covered by the functional assessment, so they know what areas to include in their evidence:

#### **Physical activities**

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

#### Mental, cognitive & intellectual activities

- 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

In addition, you could be found to need ESA if it would pose a 'substantial risk' to your health or to the health of someone else if you were required to work.

**IMPORTANT:** If your doctor or nurse thinks it would pose a 'substantial risk' to your health or to the health of someone else if you were required to work, they should also include evidence about this (e.g. if you have a severely compromised immune system).



## Personal Independence Payment (PIP)

#### Key points:

- Evidence for PIP can come from any care worker not only doctors or nurses
- You don't need a medical certificate for PIP, but you should send any relevant documents you already have about your treatment and care
- PIP assessors may directly approach your GP or care worker for evidence

#### Things you must provide ...

While DWP does not require you to provide specific evidence for PIP, we recommend that you still send anything relevant which you already have. It does not need to be recent. Send this evidence in with your *How Your Disability Affects You* ('PIP 2') form. Your PIP assessor may directly contact your GP or other health/care worker if they need extra evidence. Your GP may be paid a fee to provide this evidence.

#### Extra things you might want to send ...

PIP evidence can come from anyone who is **directly** involved in your care – they do not have to be medically trained. Send reports, care plans or supporting statements from anyone who understands the impact of your condition/s on your daily life (e.g. HIV doctor, specialist nurse, GP, social worker, carer, counsellor, occupational therapist.)

IMPORTANT: Everyone who currently gets Disability Living Allowance (DLA) and still needs help with extra costs will eventually need to be assessed for PIP. PIP reassessments will start in October 2015. If you currently get DLA, you should start thinking now about what evidence you might need for your PIP claim. This will give you, your doctors and care workers time to prepare any reports you might need.

#### What information to include ...

PIP is a 'functional' assessment. PIP assessors will not make a decision based on your HIV diagnosis, only the impact it has on your ability to get around and do daily activities. When gathering your evidence for a PIP claim, it is a good idea to look at the list of PIP activities and think about which are relevant to you:

#### **Daily living activities**

- 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

If someone is writing a supporting statement or report for you, make sure they know that these are the activities which will be considered by the PIP assessor.

#### **Mobility activities**

- Planning and following journeys
- Moving around



### **Reconsiderations and appeals**

#### Key messages:

- You must have a mandatory reconsideration before making an appeal
  - Evidence must relate to your health at the time of your initial claim

You may need additional evidence to support a reconsideration or appeal of your ESA or PIP claim, if you disagree with the initial decision. To get your claim looked at again, you must first request a mandatory reconsideration from the DWP within a month of their decision. If you are unhappy with the outcome of the mandatory reconsideration you can then appeal the decision at a tribunal hearing. You cannot go straight to appeal after getting your ESA decision.

Important: If your ESA decision was 'fit for work' you will not get ESA during the mandatory reconsideration period. You may need to make a claim for Jobseekers Allowance (JSA) so you have income while you wait for your decision. If you later appeal, you will be eligible for ESA while you wait for your hearing and decision.

#### How to submit additional evidence ...

If you request a mandatory reconsideration you will get a phone call from DWP. They will ask you if you have additional evidence. It is important to take this phone call (they will normally try phoning twice) and say that you do have additional evidence. DWP will then give you a month to collect and send your evidence. If you don't take this phone call – or if you miss the deadline for your evidence - the mandatory reconsideration will be based only on the evidence you have already sent.

If you go on to appeal the decision, you can send in additional evidence with your appeal form ('SSC1'). The SSC1 must be submitted within a month of your reconsideration decision. If you need to get a specific piece of evidence and it is not ready by this deadline, you can send it in later or bring it to an appeal hearing.

#### What evidence to provide...

Any evidence provided must be about your health **at the time you made the ESA or PIP claim about which you are appealing.** Evidence for reconsiderations must be in writing. For appeal tribunals, you can also have a health or care professional come in person to answer questions from the panel.

The DWP will have sent you an explanation of their decision. Think about exactly what you disagree with and why, especially if you think the assessor did not understand your health problems. You might want to focus on these areas when asking for extra evidence from health and care professionals.

Refer to the list of activities in the functional assessment and ask your health or care professional to comment directly on these. For ESA, make sure they also consider if it would cause 'substantial risk' to the health of you or someone else if you were expected to work or to do work-related activity. If this is the case, ask them to provide detailed evidence on why this is.

Important: Try to get independent advice and support for reconsiderations and appeals, e.g. from a local CAB or HIV support organisation, or use the detailed resources which are available online from sites such as Rights Net.

#### ESA and PIP applications - when to provide evidence

**ESA** 

plus office.

Starting your claim



Completing the form



Face-to-face assessment

Send in your 'fit note' (ESA only). Fill in ESA 50 form (*Limited* 

Phone DWP contact centre **or** fill in the ESA1 form and send/take to Jobcentre

Fill in ESA 50 form (*Limited* Fill in PIP 2 form (*How your disability Capability for Work Questionnaire*) and *affects you*) and return by deadline.

Call the DWP PIP claim line.

return by deadline.

# Send in any relevant evidence you already have/ can get in time for the submission deadline.

PIP

Attend face-to-face assessment on the agreed day/time. (At-home visits can be requested but may take longer to arrange).

Attend face-to-face assessment on the agreed day/time. (Some assessors will offer this in your own home).



Bring with you any additional evidence you want considered.

DWP will let you know if your claim has been successful, the rate of payment you will receive and for what duration, and any activity requirements. DWP will let you know if your claim has been successful, the rate of payment you will receive and for what duration.

#### If you disagree with your initial decision for ESA or PIP...

Requesting mandatory reconsideration



Request a mandatory reconsideration (in writing, if possible) within a month of their decision. When phoned by the DWP, make sure they know if you have extra evidence you want to provide.

Send in any additional evidence within one month.

## If you disagree with your mandatory reconsideration decision...

Appealing

Decision



Send in any additional evidence you can get in time for the form deadline.

Submit a SSC1 form (Notice of Appeal Against a Decision of the Department for

Work and Pensions), plus your 'Mandatory Reconsideration Notice' within a month

Appeal tribunal hearing



Attend your tribunal hearing on the agreed date/time.

of your mandatory reconsideration decision.

Bring copies of any additional evidence. Ask if your health or care professional might be able to speak directly to the panel.



# Further information and advice

#### Top tips for ESA and PIP evidence...

- Send evidence that is specific to your individual situation and explains how your HIV or other conditions affect your daily life.
- Make copies of important documents. Don't send originals.
- Don't miss the deadline for sending off your application form because you are waiting for evidence to come through – this could lead to your ESA, PIP or DLA being stopped. If you do get additional evidence after the deadline for sending off your form, you can bring it to your face-to-face assessment.
- Talk to your health and care workers as early as possible about providing evidence if possible, before you start your claim. If you are expecting your doctor or nurse to provide evidence about specific barriers to work or daily activities you need to make sure you tell them as and when you experience them don't wait until you decide to make a benefits claim.
- Make sure your doctor or nurse has a copy of the NAT/NHIVNA guide on providing medical evidence for benefits claims (www.nat.org.uk/media/Files/Publications/NHIVNA\_NAT\_FME-1.pdf).

#### Do I have to pay for evidence?

Some GPs and other health and care workers will charge a fee to provide your medical information. The DWP states that you should not have to pay for this, because the assessor will directly contact the relevant health or care worker if they need more information.

There is no guarantee that the assessor will contact your preferred health or care worker, though. This is why it is important to send copies of anything relevant you already have with your form and/or bring it to your face-to-face appointment or tribunal. In some situations, you might decide to pay for evidence – for example, if you really need it for an appeal hearing.

#### More information on ESA and PIP

This guide has looked specifically at providing evidence with your claim. If you would like to know more about ESA and PIP, NAT has the following factsheets:

- NAT's factsheet on ESA: www.nat.org.uk/media/Files/Publications/Jan\_2015\_ESA.pdf
- NAT's factsheet on PIP: www.nat.org.uk/media/Files/Publications/PIP\_Factsheet.pdf

You can also stay up to date on NAT's Life with HIV website: www.lifewithhiv.org.uk

#### More information on making and appealing benefits claims

- Official Government guides: www.gov.uk/browse/benefits
- Citizens Advice guides: www.adviceguide.org.uk
- Disability Rights UK factsheets: www.disabilityrightsuk.org/how-we-can-help/benefits-information/ factsheets
- Rights Net guides: www.rightsnet.org.uk